

Dementia Informal Caregivers' Experience with
Hospital Discharge Planning Post-Discharge

by

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Abstract

Little is known about dementia informal caregivers' experience with discharge planning, and whether the discharge planning hospital team, including the physician, nurse practitioner (NP), social worker (SW), and other allied health practitioners, meet the needs of caregivers both in- and post-hospital. This interpretative phenomenological study examines dementia informal caregivers' experience with hospital discharge planning post-discharge from an Ontario urban hospital. Five informal caregivers were interviewed using semi-structured telephone interviews, and data was analyzed using Benner's interpretative analysis process (1985; 1994). Research findings suggest that dementia informal caregivers consider their role as challenging due to many stressors and demands and poor discharge planning. Informal caregivers reveal that information sharing and the arrangement of community resources during the discharge planning process was inconsistent. They felt abandoned and unsupported throughout the discharge plan, as defined by lack of communication and dissemination of caregiver resources. As a result, caregivers had difficulty understanding and managing their loved ones' health care needs after hospital discharge. Research findings can help inform discharge planning practices and standards as it pertains to dementia informal caregivers.

Keywords: dementia, Alzheimer's disease, cognitive impairment, elderly, seniors, informal caregiver, lay caregiver, dementia caregiver, hospital discharge, discharge planning, discharge process, care planning.

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Chapter 1: Introduction

By the year 2050, the world population of persons over the age of 60 will be approximately two billion (United Nations, 2015). In Canada alone, it is estimated that 5 million Canadians are 65 years of age or older, with that number expected to double by 2036 to reach 10.4 million (Statistics Canada, 2011). The leading health issues amongst Canadians 65 and older include cancers, circulatory and respiratory diseases, and endocrine and metabolic diseases, as well as mental and behavioural disorders (Government of Canada, 2010). Other issues related to aging include a decrease in functional status, and an increased risk of falls and injuries (Government of Canada, 2006; World Health Organization [WHO], 2007). According to the World Health Organization (WHO) 47.5 million people worldwide have dementia, with 7.7 million new cases every year (2015). According to the *Diagnostic and Statistical Manual of Mental Disorders*, 5th ed. (DSM–5; American Psychiatric Association, 2013) major or mild Neurocognitive Disorders (NCDs) are a classification of disorders that affect brain function. NCDs are commonly referred to as dementia, and for the purposes of this paper, *dementia* will be the term used to refer to NCDs as it is more widely used and understood.

Dementia is an umbrella term that includes a group of brain disorders which cause memory loss and a decrease in judgment and reasoning, as well as changes in mood, personality, and behaviour (Alzheimer Society of Canada, 2017a). Dementia is an incurable, progressive, degenerative, and fatal disease. The most common type of dementia is Alzheimer's disease (AD), accounting for 60 to 80 percent of cases (Alzheimer's Association, 2017a; WHO, 2015). Alzheimer's disease process begins with

deposits of harmful *plaques*, which entangle and choke brain cells. Eventually, the plaques interfere with normal brain processes, and healthy brain cells degenerate and die; unfortunately, there is no cure for AD (Alzheimer Society of Canada, 2017b). Other types of dementia include Vascular dementia, dementia with Lewy Bodies (DLB), mixed dementia, Parkinson's disease, Frontotemporal dementia, Creutzfeldt-Jakob disease, Huntington's disease, normal pressure hydrocephalus and Wernicke-Korsakoff syndrome (Alzheimer's Association, 2018).

Two to 10 percent of all dementia cases begin before the age of 65, and the prevalence doubles every five years (WHO, 2012a). Although dementia mostly affects older people, it is not a normal part of aging (Alzheimer Society of Canada, 2017a). According to the Alzheimer's Society of Canada (2017c), 564,000 Canadians are currently living with AD and other types of dementia. This number is estimated to increase to 937,000 within 15 years (Alzheimer Society of Canada, 2017c). In Ontario, one in 10 seniors live with some form of dementia, and this number is expected to increase from 200,000 in 2015 to 300,000 by 2017 (Ministry of Health and Long Term Care [MHLTC], 2015). AD is both a national and global issue.

There are distinctive and progressive signs, symptoms, and behaviours of AD, characterized by mild-early stage, moderate-middle stage, and severe-late stage. These stages can overlap, and one can progress rapidly, or slowly, through each stage (Alzheimer's Association, 2017b). An individual in the early stages of AD may function independently but will begin to have memory lapses, including forgetting familiar words, locations, and everyday objects, as well as losing or misplacing objects (Alzheimer's Association, 2017b). A person with a moderate stage of AD will require more assistance

in managing their activities of daily living (Alzheimer's Association, 2017b). Signs and symptoms at this stage include persistent confusion and forgetfulness, behavioural and personality changes, increased risk of wandering, changes in sleep patterns, and incontinence of bladder and/or bowel (Alzheimer's Association, 2017b). In the final, and most severe, phase of AD the individual will require full-time, around-the-clock assistance with daily personal care. They will also lose awareness of recent experiences and immediate surroundings, as well as their ability to ambulate, communicate, and even swallow (Alzheimer's Association, 2017b). The primary goals for dementia care include early diagnosis, treating symptoms, and educating and supporting caregivers (WHO, 2012b).

One in five Canadians aged 45 and older provide some form of care to seniors living with long-term health problems (Statistics Canada, 2008). For the purpose of this study, the term *informal caregiver* (IC) refers to an individual who provides care and assistance, without pay, for family members and friends in need of support as a result of physical or cognitive impairments (Canadian Institute for Health Information [CIHI], 2010).

Seniors who receive care at home, including persons with dementia, are often cared for by a spouse. When the person with dementia is divorced, widowed, or never married, this care may fall to adult children (CIHI, 2010). These ICs are predominately female, with an average age of 62-67 years (García-Alberca et al., 2013; Heo & Koeske, 2012; Quinn, Clare, McGuinness, & Woods, 2012).

According to the WHO (2012a), the IC's role in caring for the needs of a person with AD, and other types of dementia, include the following: 1) in the early stages of

dementia, the IC becomes aware of the changes and prompts the person to seek assessment; 2) following a diagnosis, the IC provides emotional support while trying to maintain their loved one's independence; 3) in the middle stage, the IC role becomes more supervisory as the IC has to assist with personal care, activities of daily living (ADLs), and instrumental activities of daily living (IADLs) such as housekeeping and cooking; 4) in the late stage of dementia, the recipient of care is fully dependent on the IC for total assistance with feeding, bathing, toileting, dressing, and mobilizing. ICs often experience emotional and physiological burdens, and the quality of the relationship can impact the well-being of an IC and the level of care they provide (Quinn, Clare, & Woods, 2009). Indeed, up to 75 percent of ICs will develop psychological illnesses (García-Alberca et al., 2013). Moreover, studies have shown informal ICs have increased strain, burden, and stress (Brangman, 2006; Campbell et al., 2008; Heru, Ryan, & Iqbal, 2004), which affects their mental and physical health (Ekwall & Hallberg, 2007).

Dementia, including AD, also has an enormous economic impact on the health care system, and places financial constraints on ICs (WHO, 2012b). The global cost of dementia has increased from \$604 billion US in 2010 to \$818 billion US in 2015 (Alzheimer's Disease International [ADI], 2015). The annual cost Canadians spend on caring for those living with dementia is \$10.4 billion (Alzheimer's Society of Canada, 2017c). "In 2011, ICs spent over 444 million unpaid hours looking after someone with dementia. This figure represents \$11 billion in lost income and 227, 760 full-time equivalent employees in the workforce. By 2040, ICs will spend 1.2 billion unpaid hours per year" (Alzheimer Society of Canada, 2017d).

Persons with AD have various health care conditions that result in emergency room visits and hospital admissions. The number of emergency visits by seniors is higher in comparison to any other population group (Albert, McCaig, & Ashman, 2013). In Canada, dementia ranked sixth among the most expensive causes of hospitalizations by diagnosis from 2012-2013 (CIHI, 2013). Research supports that persons with dementia are at higher risk for hospital admission due to cardiovascular and neurological diseases, as well as respiratory and urological infections (Carter & Porell, 2005; Phelan, Borson, Grothaus, Balch, & Larson, 2012; Toot, Devine, Akporobaro, & Orrell, 2013; Tuppin, Kusnik-Joinville, Weill, Ricordeau, & Allemand, 2009). Persons with dementia are also more likely to be admitted with psychiatric crisis and behavioural disturbances, syncope, dehydration, and falls and fractures (Malone, Mucha, McLaughlin, Sklar, & Harley, 2009; Mukadam & Sampson, 2011; Natalwala, Potluri, Uppal, & Heun, 2008; Nourhashemi et al., 2001; Tuppin et al., 2009; Toot et al., 2013). An increase in dependency to complete activities of daily living is also associated with a higher risk of hospitalization (Andrieu et al., 2002; Toot et al., 2013).

The social worker and other members of the interprofessional team, including an Adult Nurse Practitioner (Adult NP) and or Primary Health Care Nurse Practitioner (PHC NP), provides discharge planning for patients with dementia in the hospital setting. NPs can “diagnose, order and interpret diagnostic tests, and prescribe medications” (College of Nurses of Ontario [CNO], 2017b). The Adult NP and PHC NP can work with the adult patient population in various specialty areas, whereas the PHC NP can provide care to all ages (CNO, 2018; Council of Ontario University Programs in Nursing [COUPN], n.d.).

In Ontario, the CNO provides three specialty certificates for NPs, including adult, paediatric, or primary health care (CNO, 2017b).

During the hospitalization of a person with dementia, ICs also play a significant role. They provide health care providers with a patient's medical history, a description of the patient's signs and symptoms, and a list of medications. They also assist with hands-on care, advocating and making care decisions on the patient's behalf (Bull & Roberts, 2001; Efraimsson, Sandman, Hydén, & Holritz Rasmussen, 2006; Popejoy, 2011). The IC is also involved in the hospital discharge planning process, working alongside the health care team as they prepare the patient and IC to return to the home environment. Researchers have found that dementia ICs deemed hospital discharge planning processes as inconsistent and inadequate, consisting of insufficient communication, lack of involvement of the IC, and nondisclosure of vital information (Cox, 1996; Bauer, Fitzgerald, & Koch, 2011; Bauer, Fitzgerald, Koch, & King, 2011; Fitzgerald, Bauer, Koch, & King, 2011).

As a Registered Nurse (RN) working in the emergency department, I have witnessed first-hand the challenges of providing care for elderly persons with dementia. Caring for dementia patients requires a holistic approach, including psychosocial assessments, medication administration, pain management, and health education for patients and their families. What I found most challenging was managing behaviours such as confusion, agitation, and aggression. By identifying my own challenges, I became more empathic toward ICs, who are often spouses and children. Through conversations with ICs, I became enlightened about many of their caregiving challenges, including the physical, emotional, and financial burdens. During these conversations,

many ICs requested information about community resources to support them in their role. I provided them with information about the Alzheimer's Society of Canada and Local Health Integration Networks (LHINs) (formerly known as Community Care Access Centers [CCACs]). I also knew that once a patient was admitted to the hospital, the IC would be involved in the hospital discharge discharge, which would provide them with further supports and community resources. Although I was aware of the importance of offering support to these ICs, the focus of the emergency department was providing medical and nursing interventions for the patient. I relied on the discharge planning that would be offered by the in-patient units, and knew the social worker collaborated with other hospital staff including physicians, Adult NPs, nurses, physiotherapists, occupational therapists, and care coordinators from the LHINs to plan and prepare both the patient and IC for hospital discharge. Was this discharge planning truly meeting the needs of the dementia ICs? I began to question this as caregivers often returned with their loved one to the emergency department, and I became more interested in their experiences of the discharge planning process. I wanted to understand its benefits, particularly from the perspective of the ICs.

According to Prorok, Horgan, and Seitz (2013), the discharge experiences of dementia ICs post-discharge offers valuable information about issues related to service delivery. A literature review conducted by Mockford (2015) found there is limited research examining family caregivers' perspectives of hospital discharge of loved ones with dementia. Ten studies were included in this review. Of these, four were from the USA (Bradway et al., 2012; Cox & Verdieck, 1994; Cummings, 1999; Ghatak, 2011; Naylor, Hirschmann, Bowles, Bixby, Konick-McMahon, & Stephens, 2007), three from

the UK (Gage et al., 2015; Newens, Forster, & Kay, 1994; Whittamore, Goldberg, Bradshaw, & Harwood, 2014), two from Australia (Bauer, Fitzgerald, & Koch, 2011; Bauer, Fitzgerald, Koch, et al., 2011; Fitzgerald, Bauer, Koch, & King, 2011; Hancock, Chang, Chenoweth, Clarke, Carroll, & Jeon, 2003), and one from Taiwan (Shyu, 2000). This study aims to build on previous research, exploring the experience of ICs in Ontario post-discharge planning from Trillium Health Partners Credit Valley Hospital (THP-CVH) with hopes of informing discharge-planning practices on an individual, organizational, and policy level.

Chapter 2: Literature Review

When patients with dementia are admitted to the hospital, oftentimes they are accompanied by ICs. These caregivers, who are often spouses and children, are also responsible for their loved ones after discharge. Therefore, it is important for discharge planners to provide them with support and resources to continue adequate care within the home setting. The purpose of this research is to understand the experience of a dementia caregiver post-discharge from a hospital in Southern Ontario. In order to better understand the challenges and issues embedded in hospital discharge planning experienced by ICs, a literature review examining previous research on this topic was conducted.

The literature was appraised from a variety of databases, including ProQuest, Ebsco, CINAHL, and Medline. In addition, documents and research from government reports, national organizations, and governing bodies for nursing practice were consulted. Information was also gathered from the WHO, Statistics Canada, the CIHI, the Alzheimer's Society of Canada, the Alzheimer's Association, Alzheimer's Disease International (ADI), the Canadian Nurses Association (CNA), the CNO, and the Registered Nurses Association of Ontario (RNAO). Search terms for research data included: dementia, Alzheimer's disease, cognitive impairment, elderly, seniors, informal caregiver, lay caregivers, dementia caregiver, hospital discharge, discharge planning, and discharge process. The literature was organized using the following headings: dementia/Alzheimer's disease, informal dementia caregivers, hospital admission of persons with Alzheimer's/dementia, hospitalizations and impact on informal caregivers, person-centred care and dementia, and hospital discharge planning. The Advanced

Practice Nurse's (APNs) role in discharge planning for elderly persons using the Transitional Care Model (TCM) was also explored.

Dementia/Alzheimer's Disease

Dementia is an umbrella term that includes a group of brain disorders (Alzheimer Society of Canada, 2017a). As previously mentioned, the progression of the signs, symptoms, and behaviours of AD are characterized in the following stages: mild-early stage, moderate-middle stage, and severe-late stage (Alzheimer Society of Canada, 2017e). Symptoms include forgetfulness, difficulty communicating difficulties, and changes in mood and behavior in the early stage. During the middle stage, memory and cognitive abilities further deteriorate. By the late stage of the disease the person is typically unable to communicate and will require 24-hour care (Alzheimer Society of Canada, 2017e).

Informal Dementia Caregivers

In a recent Canadian study the age of the average IC ranged from 24 to 92, with a mean age of 62.3; the majority, 79 percent of the 642 respondents, were women (Heo & Koeske, 2012). In another Canadian study, entitled *The Impact of Relationships, Motivations, and Meanings on Dementia Caregiving Outcomes*, by Quinn et al. (2012) found the mean age for dementia ICs was 67.8. Nearly 66.9 percent of those were female, and 68.3 percent were spouses. Other than spouses, ICs are often daughters (Toribio-Díaz, Medrano-Martínez, Moltó-Jordá, & Beltrán-Blasco, 2013).

ICs often assume responsibility because of notions of moral duty and gratitude, the need to preserve a patient's dignity, and a lack of affordable residential care (Toribio-Díaz et al., 2013). The IC provides both physical and emotional support to their loved

ones. Usually, the level of IC support increases as AD progresses and the affected individual's needs change (WHO, 2012a). ICs provide care to loved ones through supporting ADLs such as personal care, bathing, grooming, dressing, eating, and toileting, as well as IADLs such as household maintenance and finances (Alzheimer's Association, 2017c; WHO, 2012a).

A systematic review conducted by McCabe, You, & Tatangelo (2016) examined 12 qualitative studies that reported on ICs of community-dwelling older adults with dementia. In four studies, ICs explicitly reported a need to support and assist with their loved one's ADLs, including feeding, mobility, and toileting, as well as IADLs, including meal preparation, housework, and help with finances (Ball et al., 2015; Brown & Alligood, 2004; Furlong & Wuest, 2008; Söderhamn, Dale, & Söderhamn, 2013).

In two of the four studies cited above, ICs reported needing support to help with care recipients' physical functioning, primarily in the context of meeting difficulties in managing their behavioural problems (Ball et al., 2015; Brown & Alligood, 2004). In two of these studies, as well as a study conducted by Chan et al. (2010), ICs expressed a need for support in managing care recipients' Behavioural and Psychological Symptoms of Dementia (BPSD), such as aggression, agitation, and irritability (Ball et al., 2015; Brown & Alligood, 2004; Chan et al., 2010). Research suggests that ICs can experience caregiver burden, as well as depression, by managing a loved one's ADLs, IADLs, and dealing with Alzheimer-induced behaviours (Toribio-Díaz et al., 2013).

Caregiver burden is defined as the physical, psychological, emotional, and financial challenges that come with providing care (Dang, Badiye, & Kelkar, 2008). Influences contributing to IC burden can be separated into two categories, known as

patient and IC factors (Chiao, Wu, & Hsiao, 2015). Patient-related factors contributing to IC burden include the stage of dementia, behavioural disturbances, psychiatric symptoms, and functional deficits with performing ADLs (Etters, Goodall, & Harrison, 2008; Shankar, Hircarechman, Hanlon, & Naylor, 2014; van der Lee, Bakker, Duivenvoorden, & Dröes, 2014).

A longitudinal cohort study, conducted by Reckrey, DeCherrie, Kelley, & Ornstein (2013), explored the relationship between IC burden and elderly persons' characteristics living at home. The study also examined if IC burden was related to higher patient health care usage. Study participants consisted of 214 patient-caregiver dyads. Data was collected using telephone interviews, and asked ICs questions about demographics and caregiver burden. ICs were also asked to complete the Caregiver Burden Inventory (CBI) tool. Health care utilization within six months was evaluated by the total number of phone calls to and from the practice setting, as well as the number of home visits by medical service providers and social workers. Reckrey et al. (2013) found ICs more likely to experience burden were non-White, children, or spouses of the patient, and they spent over 40 hours a week helping their loved one with ADLs and IADLs. There was no association between the number of calls and visits in relation to higher levels of caregiver burden.

In a qualitative cross-sectional study, Lopez, Romero-Moreno, Marquez-González, & Losada (2012) examined the correlation between spirituality, self-efficacy, and the level of the IC's well-being. One hundred and twenty-two dementia family caregivers were participants in this study. Data was collected about IC stressors, daily caregiving hours, frequency of behavioural problems, functional status of the person with

dementia, the IC's appraisal of BSPD, and the caregiver's personal resources, including self-efficacy, spiritual meaning, social supports, and levels of depression and anxiety in the IC. Participants were divided into four groups, corresponding to four profiles defined by their scores on spiritual meaning and self-efficacy. The profiles included low self-efficacy and low spirituality (LELS), high self-efficacy and low spirituality (HELS), low self-efficacy and high spirituality (LEHS), and high self-efficacy and high spirituality (HEHS). The results found no difference in stressors, appraisal, and personal resources among the groups. ICs in the HEHS group had significantly lower depression scores compared to those within LEHS. According to Lopez and colleagues (2012), understanding the effects of spirituality and self-efficacy and their relationship to the emotional functioning of dementia caregivers would assist in better tailoring support for dementia caregivers. Spiritual coping strategies, such as prayer or meditation, as well as social support from the community, are also needed to combat depression in ICs.

Heo and Koeske (2012) conducted a study examining the role of underlying structures in the relationships between religious coping, burden appraisal, and depression in AD caregivers by analyzing baseline data from the Resources for Enhancing Alzheimer's Caregiver Health (REACH) II study, which used 642 ICs. The variables measured included religious coping using the Brief RCOPE, a three-item questionnaire, four-point scale to measure: 1) religious support, 2) spiritual connection and, 3) problem solving. Religious behaviour was measured using two questions: 1) how often the participant attended religious services and activities, and 2) how often the participant prayed or meditated. A five-point scale (0=never to 5=nearly every day) was used to help answer the questions. Caregiver burden appraisal was measured using the Zarit Caregiver

Burden Interview, 11 items with a five-point scale. Depression levels in ICs were assessed using the short version of the Center for Epidemiological Studies-Depression (CES-D) scale, rating the frequency of symptoms using a three-point scale. Other measures collected included IC demographics such as race and a self-rated physical health level using a five-point scale—zero meaning excellent and five meaning poor. Findings indicated that religious attendance was associated with more prayer and meditation, and higher levels of religious coping. Consequently, religious coping was associated with lower burden appraisal, as well as lower depression rates. ICs who reported feeling burdened were more likely to be depressed, whereas better self-rated physical health was related to more practice of prayer and/or meditation. There was no correlation between self-rated physical health and burden appraisal with depression.

Similarly, Huang et al. (2015) explored the coping strategies of 57 ICs of patients with dementia. Coping strategies were assessed using the Ways of Coping Checklist, and burden was assessed using the Chinese version of the CBI. Results of this study indicated that ICs dealt with patients' behaviour by using avoidance. In turn, depression problems in ICs were associated with avoidance and wishful thinking. The authors concluded that avoidance strategy is not effective, and can lead to increased stress and misery. This study suggests that health care providers should train ICs to use problem-solving coping techniques.

Nearly 28 percent of Canadians 15 years and older caring for a loved one or friend with long-term health conditions, disabilities, or needs related to aging reported at least five symptoms of psychological distress such as depression, feelings of isolation, and disturbed sleep (Statistics Canada, 2013). The rates of IC distress among clients with

impairment in either ADLs or communication were more than double compared to those clients without such impairments (CIHI, 2010). In addition, ICs taking care of someone with impairment with IADLs were four times more likely to be distressed than those without (CIHI, 2010).

IC distress does not only take place in the home but can also transcend into the hospital environment, since those with AD are often hospitalized and ICs are frequently the support system for the patient before and during hospital admission (Goodwin & Happell, 2006); they are also involved in patient care and care decisions (Efrainsson et al. 2006).

Hospital Admission of Those with Dementia/AD

Phelan et al. (2012) examined if dementia was related with higher rates of, or causes for, hospitalization. The total number of participants included 3,019 persons with dementia. Results from this study indicated that persons with dementia, in comparison to those without, often have higher hospital admission rates for health conditions involving the circulatory, genitourinary, infectious, neurological, and respiratory systems. Causes for hospitalization, such as bacterial pneumonia, congestive heart failure, dehydration, duodenal ulcers, and urinary tract infections, were significantly higher among persons with dementia.

Tolppanena et al. (2015) also compared the health care services used by all community-dwelling persons diagnosed with dementia compared to those without. Data from 2006 to 2009 was collected from the Finland National Hospital Discharge Register, and participants included 948 persons with AD and 27,948 without. Results indicated that 83 percent of persons with AD were admitted to hospital at least once, in comparison to

72.5 percent of persons without AD. On average, the length of hospital admission for persons with AD was 37 days and 15 days for persons without AD. Furthermore, persons with AD had higher admission rates and more hospital days of admission due to mental and behavioural disorders, injuries, and infectious diseases, as well as illnesses of the circulatory, nervous, respiratory, genitourinary, and endocrine systems.

In another study, the rate of hospital admission among community-dwelling patients with AD was examined. Study participants included 827 AD patients with data collected from 1991 to 2006. Findings showed that 542 (66%) were hospitalized at least once and 389 (47%) were hospitalized two or more times, with a median of three days spent in the hospital per year. Reasons for hospitalization included syncope or falls (26%), ischemic heart disease (17%), gastrointestinal disease (9%), pneumonia (6%), and delirium (5%) (Rudolph et al., 2010).

Impact on the informal caregivers. During hospitalization, ICs often accompany the person with dementia. Higgins and colleagues found that open communication and involvement in decision-making were important factors in decreasing stress in ICs (Higgins, Joyce, Parker, Fitzgerald & McMillan, 2007). Clissett, Porock, Harwood, and Gladman (2013a) also conducted a qualitative research study to examine the experiences of family caregivers of people with cognitive impairment during a hospital admission. Participants were family caregivers of 34 elderly persons diagnosed with cognitive impairment. Clissett and colleagues found that a hospital admission of a relative with cognitive impairment disrupted normal home routines and practices. Caregivers then coped with this disruption by trying to gain a sense of control, using

strategies such as staying informed, communicating and developing partnerships with hospital staff, as well as advocating for their relative.

Whittamore et al. (2014) explored patient and IC characteristics associated with IC dissatisfaction with hospital care of cognitively impaired elderly adults. The total number of participants were 600 patients (65 years and older) and 448 caregivers. Patients were either on the specialist, standard geriatric, or internal medical unit. Caregiver satisfaction with the quality of care was measured after hospital discharge or death. Additional measurements collected included both patient and caregiver strain, as well as caregiver health status at baseline, which included delirium, cognitive impairment, BPSD, and independence of ADLs. Results from this study showed that 54 percent of ICs were dissatisfied with communication, discharge planning, and medical management; yet 87 percent of ICs remained satisfied with overall hospital care. In addition, IC dissatisfaction appeared related to increased levels of patient BPSD during hospital admission, a diagnosis of delirium, and the relationship between the IC and the patient. There was less dissatisfaction from ICs of patients on the specialty geriatric and mental health units compared to those from standard units.

In a qualitative study, Digby and Bloomer (2014) interviewed seven patients with dementia along with their family caregivers. The aim of the study was to explore participant perspectives on the hospital environment using in-depth, semi-structured interviews. Overall, dementia patients and their family caregivers expressed the care received was significantly more important than the hospital's physical environment. However, both patients and caregivers valued privacy and personal space, as well as a connection to an outside space and natural environment. More specifically, family

caregivers stated it was important for the hospital to provide a welcoming environment, including having access to chairs, toilets, and refreshments, as well as other basic needs, when visiting their relative.

Jurgens, Clissett, Gladman, and Harwood (2012) conducted a qualitative study to examine why family caregivers of people with dementia were dissatisfied with general hospital care. Study participants included 35 family caregivers of 34 older patients. Thirty-one of these patients had dementia, with or without delirium, one a learning disability, and two other mental health problems. Family caregivers expressed they were physically and emotionally exhausted at the point of hospitalization of their relative with dementia; a result of difficulty managing challenging behaviours and reduced physical function. Hospital admission was found to lead to disruption of care routines, and was considered a period of crisis which heightened stress in family caregivers; regardless of quality of care given by health care professionals. Family caregivers thought health care providers were mostly concerned with delivering medical treatment and task-orientated care. Further results indicated there was a relationship breakdown between patients, family caregivers, and health care professionals. Family caregivers expressed feeling that hospital staff purposely disregarded them, or were demeaning or uncompromising. They also expressed they did not feel comfortable approaching staff to request information. In addition, ICs also expected staff to maintain their relatives' dignity, physical comfort, privacy, identity, and safety and when not met, lead to a source of concern. These expectations were influenced by prior hospital experiences. Most family caregivers also felt they had to act as advocates for the person with dementia. In this study, ICs either thought the discharge was planned well or poorly (Jurgens et al., 2012).

In general, ICs are not satisfied with the hospital care provided to a loved one with dementia, and hospital admission can increase IC distress. Given that hospital admission is a time of heightened stress for the caregiver, developing a personalized care plan, as well as providing health information and resources, can reduce caregiver burden for ICs with loved ones with cognitive impairment (Shankar et al., 2014).

Hospital Discharge Planning

Discharge planning is a process of recognizing, identifying, and preparing for a patient's anticipated health care needs after hospital discharge (Bauer, Fitzgerald, Haesler & Manfrin, 2009; Maramba, Richards, & Larrabee, 2004). Discharge planning can be seen as an instrument that improves patients' care needs post-hospitalization and bridges the gap between hospital and community care (Bauer et al., 2009). The process requires an interprofessional approach characterized by open, honest, continuous, and timely communication between health care professionals, patients, and ICs (Bull & Roberts, 2001; Fitzgerald et al., 2011; Haesler, Bauer, & Nay, 2007). According to the WHO (2010), interprofessional collaboration is "when multiple health workers from different professional backgrounds work together with patients, families, caregivers, and communities to deliver the highest quality of care" (p.7). The College of Nurses of Ontario (CNO) (2017a) outlines interprofessional collaboration as occurring when one or more members of the health care team work together to achieve a common goal.

The Registered Nurses of Association of Ontario (RNAO) (2013) developed the conceptual model for Developing and Sustaining Interprofessional Care by combining the National Interprofessional Competency Framework with the RNAO model for Healthy Work Environment for Nurses (Registered Nurses' Association of Ontario, 2013). This

conceptual model included six important domains: care expertise, shared power, collaborative leadership, optimizing profession role and scope, shared decision-making, and effective group functioning (RNAO, 2013) (see Appendix A). This model can be used to facilitate and strengthen interprofessional collaboration during discharge planning. In order to implement effective interprofessional discharge planning, timing is essential.

Effects of early hospital discharge. With the increasing number of elderly patients using health care services systems, a financial strain is posed on the health care system (Alzheimer's Society of Canada, 2017; WHO, 2012b). There were no studies that examined cognitive impairment and early discharge to home, thus it is important for research to be conducted in this area. The studies below were conducted on elderly patients with a general medical diagnosis not specifically diagnosed with dementia.

A cohort research study conducted by Nordström, Gustafson, Michaëlsson, and Nordström (2015) explored the relationship between in-patient length of stay after a fracture and risk of death after hospital discharge. The study participants comprised 116,111 patients with a hip fracture, and the measured outcome was death within 30 days of hospital discharge. Results found that a length of stay less than 10 days in hospital after a hip fracture was correlated to an increased risk of death after hospital discharge, compared to patients with a length of stay more than 11 days.

Dobrzanska and Newell (2006) lead a descriptive study to identify reasons older patients are readmitted to hospital within 28 days of discharge. Two hundred and ninety-one patients participated in the study, and data collection included patient demographics and patient records pertaining to readmissions, length of stay, and diagnosis. Dobrzanska

and Newell found a shorter length of stay was associated with increased risk of early hospital readmission.

A qualitative study conducted by Reckrey et al. (2013) describes elderly patients' experiences with emergency department visits with 28 days of discharge from an acute medical unit, as well as the experiences of caregivers and community health care professionals who provided care to those patients. Participants included 12 patients, 15 family caregivers, and 35 health care professionals. Semi-structured telephone and face-to-face, audio-recorded interviews were the methods used to collect data. According to the results, a revisit to the emergency department occurred as a result of symptom recurrence or functional decline. In addition, patients often returned to the emergency department as a result of exacerbations of cardiac and pulmonary conditions, as well as and mobility problems resulting in falls. Patients were commonly discharged from hospital if they were nearly meeting their treatment goals or plans because there was a high demand for acute medical unit beds.

As indicated in the above research, early hospital discharge can be very detrimental for elderly persons. Not meeting patient goals prior to hospital discharge can result in readmission. Hospital readmission is a problem that can potentially be addressed with successful hospital discharge planning.

Hospital discharge planning for the elderly. Several studies have evaluated the discharge planning experiences of elderly patients and their caregivers, but there are limited studies about elderly persons with cognitive impairment. Bragstad, Kirkevold, Hofoss, and Foss (2014) explored the participation of ICs during the discharge process of their elderly loved one, from hospital to home; the study included a sample of 262 ICs.

Findings confirm ICs of elderly relatives find it important to be involved in the discharge plan. ICs of the older generation (mean age of 80) reported feeling uninformed during the hospital discharge. Consequently, ICs of the younger generation (mean age of 55) had higher reports of cooperation and engagement with hospital staff during the discharge process (Bragstad et al., 2014).

In another qualitative study, Graham, Ivey, and Neuhauser (2009) assessed the needs of ethnic minority and recent immigrant seniors, along with their ICs, during the transfer from hospital to home. Participants consisted of 159 ICs of senior patients who had been discharged from hospital. The study's results revealed patients and their ICs received inadequate information and training during the discharge process, and more specifically a lack of linguistically appropriate information and social supports.

The discharge of elderly patients with dementia is significantly delicate and complex, and consists of many challenges involving the patient and the IC. Cox (1996) also investigated factors which determine IC satisfaction with the discharge plan. Information about the discharge process and IC satisfaction was collected from 179 ICs of hospitalized dementia patients. According to the findings, IC satisfaction was inherent on the amount of IC involvement in the discharge process. Furthermore, Naylor, Stephens, Bowles, and Bixby (2005) conducted a research study to identify the needs of cognitively impaired older adults who had been hospitalized, as well as that of their ICs, during the transition from hospital to home. Participants were five ICs, caring for family members with dementia, who expressed challenges with managing and negotiating care with various health care providers. Concerns included obtaining necessary information and finding appropriate resources (Naylor et al., 2005).

Three other studies have taken place, in different hospital settings, near Melbourne and Victoria, Australia (Bauer, Fitzgerald, & Koch, 2011; Bauer, Fitzgerald, Koch, et al., 2011; Fitzgerald et al., 2011). For each of the studies included, participants were 25 lay dementia caregivers, and data was collected using semi-structured interviews. ICs perceived the discharge plan as ad hoc, inconsistent, and unorganized, with limited communication by health professionals (Bauer, Fitzgerald, & Koch, 2011; Bauer, Fitzgerald, Koch, et al., 2011; Fitzgerald et al., 2011). The discharge plan typically occurred via a phone call from hospital staff, when the IC called to enquire about the patient's progress, and/or when the IC visited the facility (Fitzgerald et al., 2011). The ICs mentioned they did not receive adequate information important to their caregiving role from health care professionals (Bauer, Fitzgerald, Koch, et al., 2011). ICs felt undervalued, unengaged, and not involved in discharge decisions or post-hospital care (Bauer, Fitzgerald, Koch, et al., 2011; Fitzgerald et al., 2011). This is even if ICs sought information about patient's medical conditions, current and post-discharge care, as well as support services. They also felt health care providers failed to take their concerns seriously (Bauer, Fitzgerald, & Koch, 2011; Bauer, Fitzgerald, Koch, et al., 2011; Fitzgerald et al., 2011).

Jurgens et al. (2012) explored family caregiver satisfaction with general hospital care. Thirty-five family caregivers and 34 patients participated in the study. Jurgens and the co-authors found caregivers perceived discharge plans as poor when they were lacking in consultation. Similarly, Whittamore et al. (2014) conducted a study to identify patient and IC characteristics associated with IC dissatisfaction with hospital care of cognitively impaired elderly adults; participants included 462 ICs of cognitively

impaired patients. Whittamore and colleagues found areas of ICs' dissatisfaction included the management of the patient's medical problems, not being kept informed, and with the overall discharge arrangement. Likewise, Douglas-Dunbar and Gardiner (2007) conducted a study to identify the needs of ICs of people with dementia in the acute setting. Nine dementia ICs participated in the study once their patient was discharged from hospital. Based on their analysis of the data, ICs felt unvalued and uninvolved in the decision-making process. They also expressed that health professionals displayed poor communication from hospital admission through to discharge. The authors also concluded that discharge planning should be tailored to the specific needs of both patients and ICs (Douglas-Dunbar & Gardiner, 2007). When health care providers listen, value, and respect the views of the patients and their ICs, and acknowledge their concerns, the discharge planning processes can be successful.

Person-Centred Care and Dementia

The practice standards developed by the CNO (2017a) require nurses to demonstrate professional behaviours and actions that meet the therapeutic needs of the client. Client- or person-centred care is an important practice standard, and it is defined as an approach to create therapeutic relationships between health care providers, patients, and their caregivers (CNO, 2017a; McCormack et al., 2010). Person-centred care focuses on the person as a whole, including that of their overall health care experience, rather than the biomedical model, which views the person as simply requiring diagnosis and treatment for a disease (Olsson, Jakobsson Ung, Swedberg, & Ekman, 2013; Starfield, 2011). This approach is underpinned by values of respect for persons and an individual's right to self-determination, empowerment, and understanding (McCormack et al., 2010).

The literature on person-centred care and how it affects, and improves, the care of a person with dementia has been explored in many studies. In particular, Edvardsson, Fetherstonhaugh, and Nay (2010) studied the significance of person-centred care with a variety of participants that included 37 staff in residential aged care, 11 people with early onset dementia, and 19 family members of patients with dementia. Results indicated staff consistency, as well as practising flexibility, in order to meet the needs of the person with dementia were essential. They also showed that the core goal of person-centred care was promoting a continuation of self and normality. This could be achieved by getting to know the person with dementia, welcoming the family, providing meaningful activities, and personalizing the patients' environment (Edvardsson et al., 2010). Furthermore, Fetherstonhaugh, Tarzia, and Nay (2013) explored the importance of decision-making for persons diagnosed with mild-moderate dementia. Study participants included six people diagnosed with dementia. Findings suggested persons with dementia would like to maintain their ability to make decisions, or be involved in decision-making, until the progression of the disease became too severe.

Clissett, Porock, Harwood, and Gladman (2013b) conducted another study to explore person-centred care for people with dementia. Participants included 29 elderly patients and their caregivers, and findings demonstrated that health care professionals in the hospital setting do not always implement person-centred care for people with dementia. There were many missed opportunities to promote continuity of care and appropriate communication for individuals with dementia. Other missed opportunities included involving them in activities and making decisions, as well as promoting personal, physical, and physiological comfort (Clissett et al., 2013b). Person-centred care

focuses on the patient and caregiver at all junctures of the health care system.

Transitional models use a person-centred focus to improve patient outcomes along the health care continuum.

Transitional Care Model

The Transitional Care Model (TCM) (see Appendix B) was developed by Mary D. Naylor and a team of professionals at the University of Pennsylvania, School of Nursing to create a hospital discharge model for the elderly population, with the goal to improve their health outcomes (Naylor et al., 2005). The TCM model was chosen as a framework for this study and not the RNAO Care Transition guidelines because Naylor's model was one of the foundations for the Care Transition guidelines.

The TCM was conducted by a nurse with a Masters of Nursing degree; either a Clinical Nurse Specialist (CNS) or a NP who specialized in adult health, acute care, or gerontology, and had post master's five years of nursing experience in these areas (Naylor et al., 2007). When applying the TCM, the CNS or NP conducts an in-hospital assessment, and collaborates with the interprofessional team to reduce and prevent adverse events and functional decline. They also prepare an evidence-based plan of care to meet the patient's and their IC's needs and goals by conducting home visits and ongoing telephone support for approximately two months post-discharge. The CNS or NP role includes performing comprehensive assessments, symptom management, and patient and caregiver education, as well as identifying service needs. The comprehensive assessment is used to develop an individualized patient-care plan. Overall, the CNS or NP is involved in care coordination, advocacy, and educator, providing home visits as well as phone contact (Naylor et al., 2007).

The TCM has been tested with cognitively intact older adults in previous research (Naylor, 1999; Naylor et al., 2005). A randomized controlled trial was conducted to examine the effectiveness of the transitional care intervention delivered by APNs for elders hospitalized with heart failure. The study included 239 participants 65 years and older. The intervention group received a three-month, APN-directed discharge plan, and were also involved in a home follow-up protocol study. Follow-up was conducted 52 weeks after hospital discharge to measure time of first rehospitalization or death, as well as the number of re-hospitalizations, quality of life, functional status, associated costs, and satisfaction with care. Results showed the patients in the intervention group had fewer readmissions and lower total costs compared to the control group receiving standard care (Naylor, 1999; Naylor et al., 2005).

In another study, Bradway et al. (2012) identified the barriers and facilitators associated with implementing the TCM with a population of cognitively impaired older adults and their family caregiver. Fifteen patients and caregivers participated in the study. Results indicated that patient and caregivers received the necessary information and knowledge during the transition from hospital to home.

Advanced Practice Nurse: Role in Discharge Planning

According to the CNA (2008), an APN is an “umbrella term describing an advanced level of clinical nursing practice that maximizes the use of graduate educational preparation, in-depth nursing knowledge, and expertise in meeting the health needs of individuals, families, groups, communities and populations” (p.14). CNS and NP are two APN roles recognized in Canada (CNA, 2008). NPs can “diagnose, order, interpret diagnostic tests, prescribe medications, and other treatments” (CNO, 2018, p. 3). Overall,

NPs provide treatment and management of health conditions and overall health promotion, whereas CNSs provide specialty nursing care, support, and consultation to improve practice guidelines and procedures (CNA, 2008). The NP practices in accordance to the CNO standards, guidelines, and laws (CNO, 2018).

The APN (CNS or NP) has an important role to play in the interprofessional health care team involved in discharge planning of a person with dementia and their informal caregiver, particularly those who specialize in geriatrics as they provide practical, safe, and quality care, as well as valuable expertise and support to nursing colleagues (Griffiths, Bridges, Sheldon, & Thompson, 2015).

Research has demonstrated the positive impact of APNs. Williamson, Twelvetree, Thompson, and Beaver (2012) examined the role of ward-based APNs and their impact on patient and nursing practice. Data was collected using nonparticipant observation and semi-structured interviews of participants, including five APNs, 14 nurses, and five patients. Results depicted that APNs were found to enhance communication among staff nurses, physicians, and patients. APNs often translated medical instructions for patients, as well as health care staff. They would use simple vocabulary to explain medical instructions to patients and their caregivers. APNs prepared both the patient and their caregivers by making sure prescriptions were ordered and ready, that social services arranged, and also alerted care homes able to accept patients back during the hospital discharge process.

In an empirical study, Elliot and Adams (2011) reported on, and evaluated the role, of a Dementia Specialist Nurse (DSN) in an acute hospital setting. The role of the DSN was based on a person-centred approach and significant duties included raising

awareness of dementia among staff, providing quality information for people with dementia and their families, and improving in-patient care; but the education of the DSN was not mentioned. Participants included 276 older persons, and data was collected from March to September of 2010 at a general district hospital. Results showed DSNs helped reduce delays caused by waiting for dementia screening and diagnosis by a psychiatrist. The length of stay was also reduced from an average of 11 days to nine.

Bradway et al. (2012) conducted an exploratory qualitative study to examine the barriers and facilitators of the TCM model intervention implemented by advanced practice nurses for cognitively impaired elders and their caregivers. There were 15 participants recruited for this study, and three APNs provided the transitional care intervention. Each patient and caregiver dyad was followed by one APN during the course of the study. Data collection included demographic characteristics of the 15 patients and their caregivers, the patients' Mini-Mental State Examination scores, mean number of comorbid conditions, and data indicating the relationship between patient and caregiver. Further data collection was taken from individual written summaries by APNs about clinical and social events, individualized interventions and their outcomes, a summary of the patient's clinical condition, any additional information about the patient and caregiver dyad relationships at study discharge, and a summary of the APN's experience with discharge planning. In addition, case conferences were held between APNs and two of the study co-investigators to review each patient/caregiver dyad currently enrolled in the study. A total of 15 narrative case summaries written by APNs, as well as field notes from biweekly case conferences, were used to extract research findings. No direct feedback from the patient and caregiver dyad was included in the data

selection. After data analysis, Bradway and colleagues (2012) found APNs were able to identify specific gaps in knowledge and educational needs among patients and caregivers, as well as tailor information and individualize approaches. As a result, APNs fostered patients' and caregivers' independence in making decisions and problem-solving.

In the hospital where the present research study took place, the discharge planning processes included an NP. The role of this NP was the same as previously described in the TCM (Naylor et al., 2007), except they did not continue to provide ongoing telephone support, or ongoing home visits, after discharge from hospital. Rather, the NP worked alongside other members of the interprofessional team to coordinate and provide care to elderly patients. As a team they assessed, diagnosed, treated, and educated patients and caregivers during hospital admission, as well as during discharge planning.

Study Purpose and Aim

Dementia is a disease affecting nearly 564,000 people in Canada, and this in turn impacts ICs and the health care system (Alzheimer Society of Canada, 2017c). ICs of patients with dementia are immediately impacted by providing assistance with ADLs, IADLs, dealing with BPSDs, and providing a safe home environment for their loved ones. These caregivers will need to be well equipped to deal with BPSDs, and they will need adequate and accessible community resources to support them in their role.

The discharge experience of dementia caregivers gathered post-discharge offers valuable information about issues related to service delivery (Prorok et al., 2013). However, there is limited research on the topic of a caregiver's experience with discharge planning. A systematic review conducted by Bauer and colleagues (2009) concluded there are only a handful of studies that focus on the direct discharge needs of dementia

patients and their caregivers. Since then, the majority of research on this topic has been conducted in Australia (Bauer, Fitzgerald, & Koch, 2011; Bauer, Fitzgerald, Koch, et al., 2011) and the United Kingdom (Douglas-Dunbar & Gardiner, 2007; Jurgens et al, 2012; Whittamore et al., 2014). Based on my literature search, there are no Canadian studies on the topic. This study aims to build on knowledge from previous research and to further explore, within a Canadian setting, the experience of dementia caregivers with hospital discharge planning. Specifically, the purpose of this research is to better understand dementia caregivers' experience with hospital discharge planning post-discharge from a community hospital in Southern Ontario. The research findings can be used to improve hospital discharge planning practices for dementia patients and caregivers, including improving the dissemination of information, communication, and supports provided to ICs of dementia patients.

Chapter 3: Methodology

During hospital admission, caregivers often accompany family members. ICs are often responsible for their loved ones prior to hospital admission, during hospitalization, during discharge, and after hospital discharge. Caregivers are also typically involved in the hospital discharge planning of their loved one. This thesis paper aims to answer the following research question: What is the experience of dementia informal caregivers with hospital discharge planning post-discharge from an Ontario hospital? A qualitative approach, using an interpretive phenomenological design, helped answer this question, as it is inductive in nature and it stands to explore people's experience by bringing the researcher and participant in a close relationship (Morse, 2012).

Interpretive Phenomenology

Interpretive phenomenology goes beyond description and seeks to understand the meaning embedded in life experiences (Mackey, 2003; Tuohy, Cooney, Dowling, Murphy, & Sixsmith, 2013). It is holistic, and it seeks to study the whole person and situational context, rather than isolating personal and situational variables (Benner, 1985). It recognizes people's realities are influenced by the world in which they live, and that experiences are linked to social, cultural, and political context (McConnell-Henry, Chapman, & Francis, 2009; Koch, 1995) rather than viewing the person as distant from the social world as in descriptive phenomenology (Benner, 1985; Flood, 2010). It is vital to understand individual experience cannot occur in isolation of their culture and social context, and/or historical period in which they live (Benner, 1985; McConnell-Henry et al., 2009; Koch, 1995). Interpretations of human experiences, such as the experience of discharge planning of dementia caregivers, can have different meanings based on context.

Study participants may have different experiences based on their past experience, culture, support systems, and coping mechanisms, just to mention a few.

The researcher is inseparable from assumptions and preconceptions about the phenomena under investigation (McCance & McIlfatrick, 2008). “Co-constitutionality” is the notion that meaning can be formulated through the blend of participants’ and researchers’ understanding (Flood, 2010). It is also important for researchers to acknowledge and identify their pre-understandings, so readers are clear about the study’s context and possible influencing factors (McConnell-Henry et al., 2009). Nurse researchers often decide to adopt a Heideggerian approach, which rejects “bracketing,” or the concept of putting pre-assumptions of the research topic aside (Benner, 1994; McConnell-Henry et al., 2009). According to Heidegger’s approach, bracketing is impossible in interpretive research since “understanding is never without presuppositions. We do not and cannot, understand anything from a purely objective position” (McConnell-Henry et al., 2009, p. 9). Due to the perceived difficulties in achieving bracketing, this study also adopted Heidegger’s approach for interpretive research.

My pre-understanding of the discharge planning experiences of ICs of persons with dementia began while working in the emergency department as a Registered Nurse. On a number of occasions, patients with dementia had reoccurring admissions to the emergency department, and in some cases these patients were recently discharged from the hospital. Their family caregivers stated feeling ill-prepared to return home during the hospital discharge. ICs also expressed that the communication between the health care team presented many challenges, including receiving necessary information and communication about resources to assist them in their caregiving role. These

conversations and revelations lead to me to want to explore this phenomenon.

Consequently, as an emergency department nurse, I often questioned myself: How do dementia ICs perceive the hospital discharge? Thus, I wanted to understand dementia informal caregivers lived experience with hospital discharge planning.

Research Context

The participants for this study were recruited from a Trillium Health Partners (THP) hospital, specifically the Credit Valley Hospital (CVH) site. The hospital is over 1 million square feet, and has 382 beds for in-patient care (Trillium Health Partners, n.d.). Services offered at this hospital range from acute care services to community based and specialized programs. The main entry point is the hospital's emergency department, which sees more than 90,000 patients yearly (THP, n.d.). From personal experience, many of these patients are elderly, but the actual number, or percentage, of elderly persons seen each year at THP CVH could not be obtained by this researcher. According to the Ministry of Health and Long Term Care, one in 10 seniors are living with some form of dementia in Ontario (MHLTC, 2015).

Once an elderly patient with dementia, is admitted to the hospital the staff begin a hospital discharge that is intended to prepare the patients and their ICs to return to the home environment. Staff involved in the discharge plan of patients with dementia and their ICs include social workers, Adult NPs, staff nurses, occupational therapists, and physiotherapists. Their work is collaborative in the sense that the common goal is to prepare, implement, and execute a safe and effective hospital discharge. Although the social workers are ultimately responsible for processing the discharge planning documents and coordinating resources, other members of the interprofessional team are

actively involved by providing specialty consults, information, and community resources to patients and their ICs. The discharge information, such as reading material and information about community resources, are provided based on patient and family needs. Information and resources given by the social worker may include a list of retirement homes, and contact information for the Alzheimer Society of Peel and the LHIN. The social worker can send a referral to the Mississauga Halton LHIN to request for community based services for the patients and their ICs. These services include nurses, nurse practitioners, occupational therapists, physiotherapists, speech and language pathologists, dietitians and social workers in the community for follow-up, as well as for non-professional services like a personal support worker (PSW) (MH LHIN, 2017). In essence, the hospital discharge plan is collaborative and incorporates both interprofessional staff team meetings and family meetings with patients, ICs, and staff. As previously mentioned, once the patient and the IC leave the hospital, the discharge planning is complete and there is no evaluation of the discharge.

Research Participants

The research participants consisted of ICs of a person diagnosed with dementia who had been admitted to the hospital and discharged to a private dwelling or retirement home (RH), excluding long-term care (LTC) homes, after hospital discharge practices as described above.

Inclusion criteria for participants included a primary IC of a person diagnosed with dementia admitted to the hospital serving as the research setting, and then was discharged from hospital to home. The IC had to be over 18 years of age, English-speaking, and able to provide consent. The patient and IC also had to have received a

hospital discharge planning process managed by a social worker and other members of the interprofessional hospital team. Exclusion criteria included non-English-speaking ICs, given that the researcher only speaks English. In addition, ICs unable to provide consent were excluded from this study.

A purposive sample of five participants was chosen for this study, using the inclusion and exclusion criteria. This is consistent with a phenomenological design study, which typically has fewer than 10 participants (Polit & Beck, 2012). Similar research to this study done by Naylor et al. (2005) conducted a study with five patients to identify the needs of cognitively impaired hospitalized older adults and their ICs during the transition from hospital to home. Sample size was ultimately based on saturation, which is when qualitative data renders no new findings and only a repetition of information (Polit & Beck, 2012). Saturation is met when ICs expressed the same experiences about their hospital discharge plan (Polit & Beck, 2012). In this study, there were reoccurring themes emerging from the data after the first three participants.

The participants consisted of four female and one male IC, which is consistent with the literature and which supports that ICs are primarily women, including wives and daughters (Toribio-Díaz et al., 2013). Research suggest 34 percent of Alzheimer's ICs are women aged 65 years and older (Alzheimer's Association, 2017d). Thus, this sample was typical. The relationship between the patient and IC included one aunt-niece, one mother-daughter, one father-daughter, one sister-sister, and one mother-son. The participants in this research study were 80 percent women, and overall participants ranged from 45 to 65 years of age. All participants had received a hospital discharge planning process, and two persons with dementia had been living at home alone prior to hospital admission and

post-hospital discharge went into retirement homes. One other patient lived alone at home prior to admission, but went to live with a relative after hospital discharge. One patient lived home alone and returned to living alone after hospital discharge. Lastly, one patient was already in a retirement home prior to hospital admission, and returned to the retirement home after discharge.

Table 1

Socio-Demographic Data of ICs of Patients with Dementia

Informal caregivers

Age range (45-65)
Gender Females 4 Males 1
Relationship of caregiver to patient with dementia Daughter 2 Sister 1 Niece 1 Son 1

Ethical Considerations

Prior to commencing the research, the study proposal obtained approval from the research ethics board at Laurentian University (see Appendix C) and the THP hospital (see Appendix D).

Recruitment and informed consent. Guided by the inclusion and exclusion criteria, a social worker and a nurse practitioner acted as recruiters for the research study (see Appendix E). The recruiters contacted prospective participants and asked if they wanted to participate in a study about the experiences of dementia caregivers with discharge planning. The recruiter obtained verbal consent and collected telephone

numbers of prospective participants to provide to the researcher. The recruiter also notified the researcher of the participants' location in the hospital, such as unit and room number.

Once recruited, the researcher met with prospective participants to provide a verbal explanation and obtain consent (see Appendix F). The consent form indicated that the purpose of the research was to better understand the experience of caregivers of dementia post-discharge from the hospital. A step-by-step procedure was also outlined in the consent form, indicating when a telephone call would be received post-discharge, what types of questions would be asked during the telephone interview, the length of the interview, and how the information would be collected and stored.

Furthermore, participants were told the study would benefit other ICs and potentially improve the hospital discharge planning processes. They were also informed about emotional strain which was considered as one potential risk factor that could result from participating in the study. If this were to occur, the researcher would provide the IC with the local Alzheimer's Society contact information to seek additional support and assistance. The consent form also informed participants that their names would be kept confidential, and explained the data would be collected and stored on a USB key; the password entrusted only to research and supervisor for five years. After, the device will be physically destroyed and any paper documents cross-shredded. Participants were informed about having the authority to decline answering questions they felt uncomfortable answering, and/or withdrawing from the study at any given time without having any impact on services the participant or patient were receiving. Those who agreed to participate in the study signed a consent form. Afterwards, the participants were

told the researcher would call to arrange a telephone interview for after the patient was discharged from the hospital. The researcher obtained the signed consent form and collected the participants' home telephone numbers.

Data Collection

Telephone interviews were scheduled within two weeks post-discharge, at a time convenient to the participants. In similar studies, data collection was done by telephone within a period of two weeks (Bull, Hansen, & Gross, 2000; Cox, 1996; Shyu, 2000). This short time period allows ICs to best recall their discharge experience. Telephone interviews were thought to be more convenient for the caregiver after leaving the hospital environment.

Verbal consent was obtained prior to the phone interview. Socio-demographic data collected included age, gender, the relationship between the patient and IC, and the patients living arrangement prior to and after the hospital admission (see Table 1). Semi-structured telephone interviews, guided by a list of open-ended questions, were conducted to obtain in-depth information about the IC's experience with hospital discharge planning (see Appendix G). This method obtained rich information and allowed the researcher to see the world from the participant's point of view (Liamputtong, 2009).

Each interview was audio-recorded, and the duration for each was approximately 30-45 minutes. Probing questions were used throughout the interview to elicit further information, as well as to verify a theme from a prior interview. This was done in order to clarify and confirm emerging data, and in effort to reach saturation of research data (Polit & Beck, 2012). The data was used to present significant patterns and themes related to

the current discharge process (Christensen, Johnson, & Turner, 2010). Audiotapes were erased, and audio recordings recorded over, after transcription. Transcripts were checked for accuracy by both researcher and supervisor.

Data Analysis

The transcribed telephone interviews were interpreted using Benner's strategies of data analysis; the processes of developing thematic analysis to find meaning and gain understanding of participants' lived experiences (Benner, 1994). Each interview was analyzed immediately after transcription of research data. The transcripts were read several times and significant words, incidents, and cases were recognized (Benner, 1985; 1994). These passages were then highlighted, and side notes about their meaning typed up (Benner, 1985; 1994). A thematic analysis was conducted to compare additional texts and passages, with significant cases initially identified, allowing for meaning in one situation to be identified in another (Benner, 1985; 1994). New themes that emerged from the research data were verified and compared by asking probing questions in subsequent interviews. Lastly, thematic analysis was conducted to explore common themes within interviews (Benner, 1985).

Benner's approach has commonly been used by nursing researchers to better understand lived experiences. For example, an interpretative phenomenological study using Benner's approach was conducted to understand the lived experience of suicide survivors in Taiwan (Tzeng, Su, Chiang, Kuan, & Lee, 2010). Mahrer-Imhof, Hoffman, and Froelicher (2007) also conducted an interpretive study using Benner's approach to understand the effects of cardiac illness on patients and their partners. Likewise, Mauleon, Palo-Bengtsson, and Ekman (2007) used Benner's analysis to interpret a study

about patients' experiences with local anesthesia and hip surgery. This current nursing research study also used Benner's interpretive phenomenological analysis strategies to better understand the experience of dementia ICs with hospital discharge planning.

Limitations Trustworthiness in qualitative research refers to having confidence in data that uses criteria which includes credibility, transferability, dependability, confirmability, and authenticity (Polit & Beck, 2012). Given the research study took place in one urban hospital this could be considered a limitation due to the lack of transferability of research findings; if the study took place in more than one setting it would increase the study's trustworthiness (Polit & Beck, 2012). Differences in location, as well as context of health care system locally, may have an influence on research transferability. For example, a rural hospital setting with a different LHIN province could result in caregivers having a different experience with discharge planning. A study conducted to understand formal and informal caregivers' perspectives of the challenges, issues, and needs in providing care for people with dementia living in rural and remote regions of Saskatchewan, Canada, found there is a need for increased availability and accessibility of services, programs, and primary-care providers and specialists to improve the diagnosis and management of dementia (Dal Bello-Hass et al., 2014).

Lack of detailed description of the study's contexts, in this case not collecting data on culture, education, or financial means, also affects the transferability of findings (Polit & Beck, 2012). Culture can have an impact on the caregiver's role, as well as coping and discharge experience. Another limitation was the small sample size, only five dementia caregivers, who participated in this study. Sample size was based on informational needs guided by data saturation, however, a greater amount of data can be

created by a larger sample size (Polit & Beck, 2012). The richness of data could have been improved by conducting multiple interviews, or going back to the same participant more than once to yield quality data, because participants provide more information after the first interview as a result of increased trust (Polit & Beck, 2012).

Research Rigour

Actions and decisions in the interpretive analysis may not always be rational, but it is assumed they will have reasonable, meaningful patterns (Benner, 1985). By staying true to the data, the meaning will be supported by the actual evidence (Benner, 1985). Expert validation, that is validation by a thesis supervisor, was sought to ensure interpretation and meaning was derived from the data (Benner, 1985).

The researcher began with excerpts of significant statements, which led back to the original transcripts and produced themes. After organizing these into specific categories, the researcher then searched for meaning among them in order to develop a meaningful interpretation of the data using the participants' words. The researcher then determined whether the themes were essential or incidental by looking at the data as a whole. The data was read and reread to understand the meaning of the text. Major themes were identified and then compared with other texts to identify common themes, following Benner's thematic analysis to ensure credibility. The text was read and reviewed by two individuals: the researcher and supervisor, to support trustworthiness and credibility. Detailed description of the research setting, study participants, and data collection and processes was provided to readers so they could infer conclusions and determine the transferability of the findings to other settings (Polit & Beck, 2012).

Chapter 4: Findings

This study examined the experiences of dementia caregivers with hospital discharge planning post-discharge. In other words, the outcomes of discharge planning. The experience of each caregiver was distinct, however, common themes were identified during data analysis, as they related to participants' experience with discharge planning after a hospital discharge. Common themes depicted from the experiences of caregiver participants that will be described in this chapter include: caregiver burden; ineffective discharge planning; ineffective; confusing process; it's not all bad: some things during discharge were helpful.

Caregiver Burden

Participants expressed their role as caregivers was stressful and demanding. They described an increased burden after the patient was discharged from the hospital, as a result of a change in the patient's health and/or functional status.

It's a big responsibility. All participants expressed their role as an IC as demanding and difficult; a "big responsibility". These responsibilities included administering medication, coordinating care with community agencies, and providing a safe environment for the patient. The following quotes further this point:

"Very stressful. And there are moments where there is reward, but on the whole, it is very stressful and very demanding." (Niece)

"You know, I had to be responsible for medications; I had to be responsible for her, letting people in, in and out of the house, and you know, stuff like that."

(Daughter 2)

“I can’t leave her on her own, so I have to ask friends to come in. And like let’s just say I’m gone for two-three hours. So that is a big, big part, yes, not to leave her alone because you know I just can’t....” (Sister)

Participants felt it was important for health care providers to understand that the act of caregiving is a big responsibility. Perhaps revealing their challenges and experiences as caregivers would help health care team members understand it is imperative to provide resources and supports in preparing caregivers to return home and assume their role as ICs.

Living with difficult behaviours. Caregivers (n=3) also expressed how difficult it was to live with their loved ones’ behaviours. These behaviours included memory loss and defensiveness when receiving care, and is illustrated by the following quote:

“So as soon as you say one thing about their memory, ‘Oh, maybe you just didn’t remember,’ suddenly there’s this huge wave of defense coming up and they want to defend themselves. ‘My memory is ok.’ They don’t understand the difference between short-term memory and long-term memory, so they get very defensive because they know they’re taking pills to help them with their memory and maybe it’s not working.” (Niece)

The following participants also explain the frustration which comes with this memory loss and subsequent defensiveness:

“She is a little bit stubborn, which I find is the worst thing. You know, if I tell her to do something, ‘I am not a baby,’ and ‘Ah, I don’t wanna do that. Just because you told me I’m not gonna take it [medication].’ But that’s just her character, she just feels like she’s still independent and she could do it on her own. So, that to

me is a bit challenging.” (Sister)

“So that’s what I’ve found difficult, you know? Being stubborn, and not wanting to eat, and not wanting to get up, and stuff like that. That was tough for me. It’s difficult.” (Daughter 1)

Although the ICs recognized the behaviours they did not always understand the progression of dementia, as some attempted to describe the patient’s behaviours as stubborn, or as part of their character, rather than associated to the behavioural progression of dementia.

Ineffective Discharge Planning

Every IC mentioned the discharge planning preparation was ineffective. Participants stated this was a result of interruptions during the discharge plan, ineffective communication, confusion with the process, a sense of abandonment, being in unknown territory, and a perceived unsafe discharge decision.

Interruptions during discharge planning. The process of discharge planning was interrupted, and at times delayed, as a result of computer-system failures, code blues, and staff availability. This frustrated the ICs (n=4). They explained:

“It just happened to be after a long weekend, so things were a little bit, ah, crazy and their computers were down.” (Daughter 1)

“When I came to pick her up, there was a code blue ... the papers weren’t ready.” (Sister)

“‘I’m going away on holidays [said the health care professional], I can’t do it till the twenty-third.’ Well, isn’t there anyone else? Are we waiting because you are going on holidays?” (Niece)

“Definitely, I felt, in fact I felt the [health care provider] was putting me on the spot, saying, ‘Well, you should’ve followed through.’ I know she was on vacation, and when my father took this fall the week before I really didn’t think they handled that well. And definitely most difficult was they, like I said, nothing was in place. Nothing was coordinated well.” (Daughter 2)

Such interruptions during discharge planning impacted the arrangement of services and provision of information, as well as the therapeutic relationship between the discharge team and the lay caregivers.

Ineffective communication. All caregivers expressed experiencing ineffective communication between themselves and the interprofessional hospital team involved in the hospital discharge planning, as well as poor communication among the hospital team and community agencies.

Between patient, informal caregiver, and the interprofessional team. Two caregivers reported receiving insufficient information about the patient’s diagnosis, results of diagnostic tests, or treatment plans during the discharge plan. For example, participants shared:

“Just trying to speak to the doctors and nurses in charge, I wasn’t quite sure of what I should know. I’m still not sure; they took x-rays of her leg and I’m still not quite sure. They said it is arthritis. Like nobody could really actually go into details for me.” (Sister)

“You know, one of our biggest concerns is X’s mobility and her weakness ... I feel that I didn’t get the support and understanding about that. Like I’m still really hazy about how she went from not walking at all, and we spent, like, 16 hours in

the emergency; nobody could figure out why she couldn't walk, and then you know two weeks later, oh yea, she can walk 40 metres, and nobody could tell us if this was gonna happen again or why it happened, or was it related to anything in particular, no! There was no understanding really of what had happened."
(Niece)

When inquiring about long-term facilities, a daughter expressed her dissatisfaction with the information she received:

"You know, like, it wasn't like, 'Let's sit down and have a meeting,' or even sitting down with my mom so we can talk about it together ... even if it was like ten minutes of 'Let's discuss this right now' ... It was just 'Here's the booklet and ... and go look at these places'." (Daughter 1)

Two caregivers admitted some valuable information was discovered by chance, or randomly through casual conversation with health care professionals, and not as part of the discharge meeting. They requested information pertaining to community resources, long-term care, and other community programs because it was not initially provided. A participant explains:

"Well she had pneumonia, and I didn't even know she had pneumonia ... and yet when she was admitted they said her temperature was up and they didn't know why. I was never told she had pneumonia until about two weeks later; I found out by accident." (Sister)

"... for the resources and I asked for it. I said you know about the nursing home that X was already on the application and in process with the CCAC, but I was asking for information on which nursing home that could possibly have a shorter

wait list and they provided me with that.” (Niece)

As well as having to ask for information, three caregivers expressed they were not clearly provided with details about the process of applying for long-term care or other community programs during the discharge plan. The following participants provide examples:

“... Like you have to really clue into the system to ask for the right resources; like, I feel like I'm pulling teeth because they, they can dump that big brochure on you about all the nursing homes, but it takes months to find five that you can actually, you know, go to; like who, who has the time, you know, to, to scout around when you already know you got a family member who is failing in health and they're all telling you to go search up five of them; but it can take a month just to get on a tour.” (Niece)

“I wasn't told what the process would be, and, so here it is: (Mrs. M) was discharged three weeks ago and I'm just now gonna get the interview to apply for crisis management.” (Niece)

“I guess if I didn't receive it I don't know what that would be. You know? The Wait At Home Program, they're called 'Wait At Home'; I think that was confusing for me because I thought that she had to go back home. I didn't realize that she could also do the 45 days at a retirement home.” (Daughter 1)

Lack of communication and explanation of diagnosis resulted in caregivers feeling unsupported, overwhelmed, and confused.

Between the members of the interprofessional team. Participants reported witnessing a lack of communication between the interprofessional team during discharge

planning. As a result of this lack of communication, two caregivers expressed receiving mixed messages and inconsistent information. The following participants explain:

“Like, so do you wanna talk about discharge?; but nobody was getting any facts right when she was being admitted.” (Niece)

“Its ... again, I'm sorry, I forget her name (the nurse practitioner); she had mentioned and she wanted to get the paperwork, or she was going to make sure someone gave this to us. They did not.” (Daughter 2.)

Daughter 2 continues to explain her experience with ineffective communication between members of the interprofessional team:

“Like, two weeks before, and then every time I spoke to someone nobody was coordinated together on what was going on. Like the charge nurse was the one that made the decision to keep him till the Friday, not the Wednesday, because I said ‘Well, when I'm moving I literally can't do it on that other day,’ and she said, ‘No ... we're concerned about him.’ His blood pressure was up, I think, and she said ‘I'll talk to the doctor,’ and doctor and the head nurse decided that no, they needed to keep him until the Friday. The next day I got a call, again like that second call from the social worker, the third call, and she said at that time ‘Oh yes, and he's fine. And he's going home on Wednesday.’ I said, ‘No the doctor is extending it till Friday’.” (Daughter 2)

Ineffective communication among the interprofessional hospital discharge team prevented ICs from receiving important information, not to mention mixed messages. Caregivers perceived the hospital discharge plan as uncoordinated. Poor communication between members of the interprofessional team also lead to ineffective communication

between the hospital and community care agencies.

Ineffective communication between caregivers and the health care team can be detrimental to ICs. Study participants reported not receiving sufficient information concerning the patient's diagnosis, results of diagnostic tests, or treatment and discharge plans. Overall, participants wanted more time, designated by discharge planners, to answer their questions and concerns, rather than giving them written information and resources to go through on their own. A participant also made the following recommendation to ensure effective communication between discharge planners and caregivers:

"I do feel, and again, I mean I know part of it could've been the summer and that they are understaffed, I think they have to be careful on making sure a department has definitely covered going over everything properly with the family." (Daughter 2)

Between the hospital and the community. Three ICs thought the transition of patients from hospital to home was not seamless, and not always well-coordinated by the interprofessional team involved in the hospital discharge plan. Issues with community services not being arranged, or delayed, took place after the patient was discharged home from hospital. A frustrated informal caregiver explains:

"I asked, 'Can you tell me when CCAC ... has that all been set up?' Nothing had been done by the hospital. So the doctor (from the retirement home) went in and saw my dad that day and requested it all. I talked to CCAC this Sunday (a week ago Sunday). The only request that they had ever had to do anything with my dad was what the doctor at Viva [retirement home] had set up. Nothing has

come from the hospital.” (Daughter 2)

“Yes, she just did, I think, they are gonna follow-up with us ... to have a meeting and all of that. I haven’t, but I don’t think I have had any information yet; I don’t recall she calling me up. Or they were gonna send me some emails.” (Son)

Another participant further questioned the process:

“Why didn’t I have somebody from CCAC at the hospital, at the meeting? They organized the meeting and there was nobody there from CCAC.” (Niece)

Confusing process. Inconsistency and difficulty navigating the many different people involved made the discharge planning process confusing for two participants; it was a hit or miss as described by this participant:

“No, I found at the hospital it was hit and miss. I did meet the nurse practitioner in geriatrics. He was up on the medicine floor for about two weeks. And even when they moved him down, I mean the only time I actually met the social worker (sigh), was at the discharge meeting.” (Daughter 2)

“I wasn’t as stressed out by it, but this is the one thing I do want to say. It’s really hard to deal with so many different people; so there are a lot of people, you know, you need to talk to, like, social worker, the geriatric specialist. I didn’t speak to directly anybody else except at the meeting.” (Niece)

Furthermore, the participants experienced inconsistencies in what was said and what was actually done with regards to arranging community services. This resulted in a delay of community services.

“My dad took the second fall in the hospital. After that they told me ‘No, CCAC is all set up’ that last week before we left. So I said, ‘Ok.’ So, we picked him

up on the Friday and moved him over ... nothing had been done by the hospital.”

(Daughter 2)

Caregivers were under the assumption plans were already in place but were in fact mistaken, as indicated in the quote below:

“I was under the assumption that she was already in crisis placement and they’re expecting that she was in the loop there. They didn’t even realize that she isn’t, you know, so this could be delayed, you know, right until she ends up right back into the hospital with a fall.” (Niece)

Inconsistencies during the discharge plan made it confusing. Caregivers found it challenging to converse with different members of the discharge team during different occasions.

Sense of abandonment. Two participants experienced feeling unsupported and alone during the overall discharge plan. They felt the need to request time to hear explanations and answer questions, beyond just providing written information. Caregivers also felt lack of support and involvement.

“You’re groping around in the dark. ... Everything just seems to be put out to dry.” (Niece)

“Instead of just handing us the book, spend an extra ten minutes with us explaining it, instead of, you know, ‘Here you go. This is what’s next and this is the way the system works and this is what we can do.’ That’s when I felt alone, you know. It was just, I was handed the booklet and I was overwhelmed ’cause there were lots of places.” (Daughter 1)

Not receiving the necessary resources and information, and/or not having such information explained was distressing for ICs. They felt like they were disregarded during the discharge plan.

Unknown territory. Caregivers had a challenge understanding the discharge plan, and all except for two caregivers were going through a hospital discharge plan for the first time. Thus, discharge planning steps and decisions were challenging and difficult at times for participants (n=2); they felt like they were in an unknown territory.

“There was a lot of things on my part to do, do you know I mean? Like, I had to go and look through the retirement home and all kinds of stuff. So that was a first experience; that was very new for me.” (Daughter 1)

“... Ahm so that’s why I asked, ‘Are there any nursing homes where there are, you know, shorter waiting list?’ But, like, you have to really clue into the system to ask for the right resources; like I feel like I’m, I am pulling teeth because they, they can dump that big brochure on you about all the nursing homes....” (Niece)

These caregivers found it challenging to manage the tasks and responsibilities related to their roles; most importantly, for the participants of this research, applying for retirement homes and long-term care homes for their loved one with dementia. Not only did ICs have to complete discharge planning tasks, they also had to advocate for their loved one during the discharge planning process.

Unsafe discharge decision? Two ICs questioned the decision to discharge the patient from hospital because of patient’s health condition, safety, or insufficient community resources. Frustrated caregivers explain:

“So they’re managing the pain, they’re masking her symptoms, she’s got bone scraping on bone. How long is this frail, little old lady going to tolerate that? And they put her back into the community, you know, in complete limbo ... she is not in a safe place when she can’t even get out of the door of her own suite by herself, like if that place burned down, someone would have to pull her out of there.” (Niece)

“Because he left the Friday after the long weekend in August, and I called them on the Tuesday, and said, ‘Look, you’ve done nothing with him over the weekend. You’ve really done nothing since the fall. You’re saying he can’t even get out of bed yet.’” (Daughter 2)

Once home, ICs are still dealing with the patient’s health issues, some of which were not completely resolved in hospital. ICs are troubled by taking on more responsibility and dealing with continual problems, including pain and safety concerns of the patient.

It’s Not All Bad: Some Things during Discharge Were Helpful

When information was provided, three ICs appreciated an explanation of the patient’s diagnosis and hospital care plan. This was indicated as one helpful aspect of discharge planning. Caregivers (n=3) expressed the most helpful people during the discharge planning were the NP and the social worker. Participants appreciated when the NP explained the patients’ diagnosis and diagnostic tests in a clear and detailed manner during discharge meetings, or simply when the caregiver was visiting. The social worker was also helpful in answering questions and providing information when requested by caregivers.

“That was most helpful. And she (nurse practitioner) answered all my questions that I had, and she helped me knit together all the diagnostics test and everything.” (Niece)

“She [nurse practitioner] really helped explain a lot of what my dad would be going through. What he would be going through later on. And this was more, sort of informal, not real formal stuff. Even at the discharge meetings I found her the best.” (Daughter 2)

“The social worker was very good, she was very good. She would often go to the chart and help me out if I would ask for something; she would go and try to help me.” (Sister)

Two caregivers had positive experiences when arranging community resources, as discussed below:

“They offered physiotherapy, which is already in place. They wanted a woman to come out and give her a bath and take care of her every day. But of course, like I said, she would not have any part of it. And I’m here, and it is a very small house. So, you know, we declined that. And an occupational therapist is coming tomorrow. Just check and make sure that everything is in, is in place. And yeah, even when I left, one of the physiotherapists there came and she gave me a little chart; that, you know, things that I should get. I already have a toilet for her, so that is very good. And they gave me all kinds of stuff. You know, explaining the medication, when to give it to her, and all that.” (Sister)

As another participant explained:

“Ah well I think the hospital arranged those people. They came in and they got my mom assistance right away, and she didn’t have to go home and be alone, or not able to take her medication; somebody is helping her. So, the Sunday and Monday she has her, she has her assistance, which I think is very, very good.” (Son)

There were some positive experiences with communication between the hospital and the community resources. When services were offered and implemented promptly, due to effective communication, the transition process was easier for the ICs. Effective communication helped the patient and caregiver understand, and navigate through, the discharge plan with less confusion.

Support is Essential

According to the participants, it is essential for discharge planners to provide caregivers with supports. These supports, such as information about community resources, were considered extremely helpful.

Information and resources. As previously mentioned, information sharing between hospital staff and ICs during the hospital discharge planning process were inconsistent. Thus, caregivers were either satisfied or not satisfied with the information they received, but one caregiver was in-between. Those satisfied (n=2) were glad to have received information pertaining to community resources and medical information during the hospital discharge plan, and (n=1) was somewhat satisfied. As participants explained:

“They have printout sheets, and they have a book that’s, um, I think it’s called ‘Long Term,’ and it’s got all the addresses of the long-term care facilities, and also, in this case, the retirement home.” (Daughter 1)

“Yeah, the nurse did come. And she gave me a list of all the medications, explained everything.” (Sister)

“Like, for some of the information [medical information], I had to keep asking; like I wasn’t quite sure what was going on.” (Sister)

“Yeah! It was very informative. I mean, like, we had never been through nothing like that, and we had nothing to compare it to, but it was very helpful and there was a lot of information, and I’m pretty sure if I’ll call on them they will volunteer more information or service, whatever is available out there.” (Son)

One caregiver expressed that community resources were given, but felt they were insufficient.

“Yeah, so, they’ve said ‘We’ll have community care come in three times a day,’ and I go, ‘That’s great ... (pause) but it’s not enough.’” (Niece)

Dissemination of information during the discharge plan varied. Generally, when information was provided, participants were satisfied. Two caregivers mentioned they received information and resources directly related to caring for a person with dementia.

“They have mentioned if I would be interested. Yes, she told. She did mention, if I would be interested for a meeting (Alzheimer’s Society caregiver support meetings); and I said yes.” (Sister)

“... how Alzheimer patients behave. And how we should prepare for it in the long-term.” (Son)

This, however, was not always provided, as explained by two participants:

“They never gave me any information about dementia at all....” (Niece)

“She [nurse practitioner] was going to make sure someone gave this to us [information about dementia]. They did not.” (Daughter 2)

One caregiver mentioned she had already received information and resources from the hospital during a past discharge, but this time no further dementia-related resources were given.

“Yes, yes, but that was done in April, not this time.... It was done in April when she fell.” (Daughter 1)

Furthermore, information and resources directly related to caring for someone with dementia were not consistently discussed. Participants can understand how to deal with the progression of Alzheimer’s and BPSD if they have more information and community resources.

Physical support. On the day of discharge, two ICs found that having equipment such as a wheelchair, as well as help to transport the patient, was helpful. Participants explained:

“But when I got there they pretty much knew that my mom was leaving, so they called the wheelchair taxi to bring us to the retirement home.” (Daughter 1)

“The wheelchair was there.... They provided a wheelchair, so that was very good; I found it very good.” (Sister)

Summary of Findings

During the actual day of discharge, participants expressed that the physical support and assistance they received were very helpful in transitioning the patient from hospital to home. Without assistance to leave the hospital, the discharge experience

would not have been complete. Making sure the patient is prepared and able to go home safely is important for caregivers.

The study's findings depict the issues and challenges that dementia ICs endure. Caregivers voiced their role as being a big responsibility, caring for their loved one's physical and emotional needs. During the discharge plan, caregivers experienced hospital interruptions, such as computer-system failures, hospital code alarms, and lack of staff availability, and found it frustrating. Other major issues included ineffective communication between the patient, the informal caregiver, and the interprofessional team, as well as among members of the interprofessional team, the hospital, and the community. Caregivers expressed that the discharge plan was confusing and inconsistent. Dissemination of information and resources was thought to be inconsistent, and caregivers were either satisfied, or not satisfied, with the information they received. Those satisfied were glad to have received information pertaining to community resources and the patient's medical information, including diagnosis and medications. On the other hand, those dissatisfied expressed that the community resources were insufficient, and they had to seek and request the information. In addition, information and resources pertaining to caring for someone with dementia were not consistently discussed. Caregivers felt unsupported and alone during the discharge planning because they felt they had to request information, and then the explanation of that information, as well as lack of support with decision-making. And as a result, caregivers felt abandoned, something which was more challenging for caregivers experiencing a discharge planning process for the first time. Challenges included not understanding the discharge plan, the steps to take, and the decisions required for them to make, as related to the discharge

plan. Even with the decision to discharge, some caregivers felt it unsafe to return the patient to the home environment, due to perceived poor health, safety issues, or insufficient community resources to support the patient.

Caregivers did find some things helpful, which included the assistance of some members of the discharge team; like the Adult NP who took the time to explain the diagnosis and diagnostic tests in detail, and the social worker who provided information about community resources when requested. Caregivers were also satisfied with the physical support they received during the discharge planning, such as access to a wheelchair and help with transportation leaving the hospital. For improving discharge planning, caregivers suggested that supports, including resources about long-term homes and community resources, would be extremely helpful. The hospital care team, as well as stakeholders in the health care system, can use these findings to implement changes in discharge planning practices.

Chapter 5: Discussion and Recommendations

A discussion of the above findings is important, in order to depict how the research can be used to improve the discharge planning processes for patients with dementia as well as that of their informal caregivers. Also presented in this chapter are recommendations for future research topics to improve discharge planning.

Preventing Informal Caregiver Burden

Caregiver burden is defined as the physical, psychological, emotional, and financial challenges ICs experience (Dang, Badiye, & Kelkar, 2008). The IC is an important person in the life of an individual with dementia. The study's participants reported the caregiver role as having significant responsibility, stressors, and demands, which may lead to IC burden. ICs expressed caring for their loved ones needs, including administering medications, coordinating care with health community agencies, and providing a safe environment, presented challenges and constraints. Plank, Mazzoni, and Cavada (2012) also found that ICs reported being responsible for everything when having to provide constant supervision and an appropriate environment for their loved one.

Participants in this current study also reported having to live with changes in behaviours of the person with dementia, including memory loss, defensiveness, and uncooperative behaviour. Wang, Xiao He, Ullah, and DeBellis (2014) found that physical burden was associated with the employment status of the IC, the duration of dementia in the patient, and the severity of the BPSD of care recipients. Emotional burden was related to increase usage of social supports by ICs. In this study, the caregivers having a challenging time in managing BPSD also expressed this. Unfortunately, for the

participants in this study, information and resources directly related to caring for someone with dementia were not consistently discussed.

Research suggests better management of dementia-related behaviours, including delusions, agitation, aggression, and anxiety, would have a positive effect on reducing IC burden (Huang, Lee, Liao, Wang, & Lai, 2012). ICs who have to deal with a high frequency of behaviour problems, but have high levels of self-efficacy, presented significantly lower levels of distress associated with depressive and disruptive behaviour problems compared to those ICs with low levels of self-efficacy (Nogales-Gonzalez, Romero-Moreno, Losada, Marquez-González, & Zarit, 2015). Lack of social supports also leads to IC burden (Wang, Xiao He, Ullah, & De Bellis, 2014).

Hospital discharge planners should provide resources to ICs to reduce caregiver burden. Resources should include counselling, group supports, adult day programs, and respite care. Research demonstrates enhanced counselling, including family and support group participation, as well as continuous availability of telephone counselling, decreases IC burden and depressive symptoms (Gaugler, Roth, Haley, & Mittelman, 2008). Support groups have also been found to improve dementia ICs' depression levels (Chu, Yang, Liao, Chang, Chen, Lin, & Chou, 2011). Respite care also provides ICs with a break from caregiving, and their loved one is cared for in a safe environment (Alzheimer's Association, 2017e). This current study did not support this finding, but nonetheless should be considered as a recommendation for future studies. The Dementia Friends Canada is a program which was funded by the government and is run in partnership with the Alzheimer Society of Canada. It was developed to help bring awareness to Canadians about what it means to live with dementia, as well as how to support affected individuals

within the community (Statistics Canada, 2016). Hospital discharge plans for dementia patients and their ICs should include information about the First Link and Dementia Friends Canada programs.

Consistency in Discharge Planning

This study found information sharing during hospital discharge planning was inconsistent, which are consistent with a previous study by Bauer and colleagues who found ICs perceived discharge planning as inconsistent, ad hoc, and unorganized, and were poorly planned (Bauer, Fitzgerald, & Koch, 2011; Bauer, Fitzgerald, Koch, et al., 2011).

Furthermore, participants from this current study experienced inconsistencies between what was said, and what was actually done, with regards to arranging community services. This resulted in a delay in receiving said services. The ICs were frustrated with community services not being arranged at all, or being delayed prior to the patient returning home after hospital discharge. Similarly, prior research has revealed that as a result of breakdowns between lines of communication, ICs do not receive required services when they are promised (Bauer, Fitzgerald, & Koch, 2011). Improved communication between staff members, patients and ICs as well as community partners is important for improving the hospital discharge planning process.

Another factor, according to the participants in this study, affecting consistency during discharge planning were the interruptions in the process; including computer-system failure, code blues, and staff availability. Wong and colleagues (2011) also found that discharge planning was a challenging task, due to manpower shortage and not having the staff to conduct multiple discharges. An area that should be further studied is

coverage plans for staff members who go on vacation or report being sick, as it pertains to the effectiveness of discharge planning.

Effective Communication

RNAO (2014) recommends the use of effective communication to share client information amongst members of the interprofessional team during discharge planning. This study found that information sharing during hospital discharge planning was ineffective at different levels, making navigation difficult. Furthermore, participants experienced inconsistencies in what was said by clinicians versus what was actually done. They felt they did not receive the information they needed, or had to request information they felt should have been given to them. This inconsistency and lack of information was stressful for the ICs, and made their role difficult to fulfill. ICs, in a prior research study, also expressed that information important to their role was often not provided (Bauer, Fitzgerald, Koch, et al., 2011). In addition, family caregivers' expectations of communication by nurses and other health professionals about care received in hospital, as well as the care needed after discharge, frequently fell short of what they considered necessary to meet their IC role (Bauer, Fitzgerald, Koch, et al., 2011).

This is consistent with other research, which indicates family caregivers had to ask hospital staff questions in order to be informed about the patient (Clissett et al., 2013a). A study conducted by Moyle, Bramble, Bauer, Smyth, and Beattie (2016) also found that access to information was difficult as a result of lack of access to medical staff. Other research found health professionals displayed poor communication, from the hospital admission until discharge (Douglas-Dunbar & Gardiner, 2007). Further research

has found ICs feel undervalued and are dissatisfied with not being kept informed about hospital discharge plans and other arrangements (Fitzgerald et al., 2011; Whittamore et al., 2014).

This research also supports what was found in a British Columbia report conducted by Donnelly, McElhaney, and Carr (2011) which was conducted to assess, and improve, the health care needs of persons with dementia in an emergency department and acute care hospital setting. ICs expressed that communication was very important and needed to be improved in general. More specifically, better transfer of information at shift change and liaisons with home and community care. ICs also reported a lack of communication between the hospital team and community care, which resulted in a delay in services, or community services not being arranged. Lack of communication also prevented ICs from obtaining the necessary information and supports required to aid them in their role. Poor communication and explanation during the hospital discharge planning left ICs feeling overwhelmed, confused, unsupported.

Chaboyer and colleagues (2016) explored how health care professionals can engage patients in communication associated with care transitions. Strategies identified included team meetings and use of patient-care boards, which can be used to communicate the patient's or the family's needs, preferences, and priorities. Communication techniques and strategies are vital in improving discharge planning practices, and in turn eliminate confusion and inconsistencies during hospital discharge.

Scerri, Innes, and Scerri (2015) also examined the quality of care for dementia persons; 33 care workers in a geriatric hospital and 10 family members of patients with dementia were interviewed. Findings suggested quality care can be obtained when

hospital staff build relationships and use appropriate communication strategies toward persons with dementia, as well as by providing quality and genuine time to engage with the patient and attend to their physical and physiological needs.

Eliminating Confusion during Discharge Planning

Participants in this study expressed feeling the discharge plan was confusing and difficult to navigate, one reason being interacting with different health professionals during the discharge plan. Research confirms ICs are more satisfied with constant communication with a single health professional, a key contact person (Digby & Bloomer, 2014). Moyle and colleagues also found ICs emphasized the importance of having one central source of information (Moyle et al., 2016). Having one specific member of the clinical team as the key contact person provides regular communication between ICs and the clinical team, ensuring ICs are involved in both decision-making and the discharge planning process (Digby & Bloomer, 2014).

ICs also expressed they were not informed about what was expected of them during the discharge planning; in other words, role confusion. ICs did not understand the process for applying to retirement homes or long-term care homes. They were not aware they needed to physically visit these homes and go for tours in order to decide the potential options for their loved one. Similarly, Moyle et al. (2016) found ICs expressed a need for information about role expectations because they were unclear about what it entailed. Guidelines to prevent role ambiguity can include a clear definition of roles of the persons involved in care, as well as the role expectations of family ICs at each step of the discharge plan.

Essential Supports

With an interprofessional, collaborative approach during the discharge planning process, health care professionals can provide dementia caregivers with the tools, resources, and supports necessary to aid them in their role. This should include knowledge about potential behaviours associated with dementia, such as wandering, restlessness, and aggression, along with education about coping strategies (Alzheimer Society of Canada, 2017f).

This study found the supports provided during the discharge plan were essential for ICs, and the lack of support for some ICs was perceived as abandonment. Essential supports included adequate information, as well as physical supports during discharge. ICs in this study expressed assistance to leave the hospital, for example help transporting the patient by wheelchair and arranging a wheelchair taxi, was required to complete the discharge plan.

Another form of support identified was information sharing. This was perceived to be inconsistent during the hospital discharge planning, and ICs were either satisfied or not with the information they received. ICs had to request that health providers to explain and answer questions, and go beyond just providing written information during the discharge. “It is important to assess the learning and informational needs of a client and their caregivers to self-manage before, during and after a transition” (RNAO, 2014 p. 24), in this case a hospital discharge. These findings are in line with a previous study, which found some ICs felt well-prepared and involved; whereas others experienced little health information, as well as poor understanding and empathy (Plank, Mazzoni, & Cavada,

2012). A systematic review conducted to examine current evidence pertaining to the informational needs of ICs of older adults with chronic health conditions found they desired to be better informed about biological/medical issues, as well as information concerning service availability (Washington, Meadows, Elliott, & Koopman, 2011). Again, ICs reported the need to be updated regularly in regard to the patient's medical condition, as well as their plan of care and discharge (Moyle et al., 2016). Plank, Mazzoni, and Cavada (2012) found ICs pointed out the importance of receiving more quantity, and quality of information rather than just a simple exchange of basic information.

Consequences of this lack of information are mentioned in other studies. Moyle et al. (2016) identified ICs as feeling confused, tense, and uncertain when they received limited information. Plank, Mazzoni, and Cavada (2012) also found ICs would seek information outside the hospital setting, due to reasons of a lack of trust toward hospital staff or a previous bad experience. ICs much rather appreciated help from individuals experiencing similar situations as they were considered more credible and trustworthy.

Bloomer, Digby, Tan, Crawford, and Williams (2016) also found that emotional support is required for dementia ICs, as the hospitalization of a loved one is stressful (Jamieson, Grealish, Brown, & Draper, 2016). Additionally, Moyle and colleagues found the hospitalization of a person with dementia is distressing and exhausting, however, the psychological needs of the IC are usually secondary rather than the main focus. ICs reported it would be helpful to have someone to talk to, in order to support them emotionally throughout the journey (Moyle et al., 2016). Emotional, informational, and physical supports have been identified as essential components of the hospital discharge

plan. Discharge care plan models, such as the TCM, incorporate these components so as to improve hospital discharge plans for dementia ICs.

Applying the Transitional Care Model

Dementia ICs need a well-coordinated and seamless discharge plan. The TCM conceptual model, developed at the University of Pennsylvania, School of Nursing by doctor Mary D. Naylor, is the proposed framework for improving discharge planning. This model is applicable because it was developed to manage health problems of elderly persons during transition from hospital to home, using advanced practice nurses in collaboration with other health care workers focused on discharge planning (Naylor et al., 2007).

Bradway et al. (2012) used the TCM in a study to examine whether patients and ICs of cognitively impaired older adults received sufficient information and knowledge during the transition from hospital to home. The model also addresses the importance of following up with the ICs post-discharge via calls and home visits. This was not the case for the ICs in this research study, yet they clearly were not satisfied with the discharge planning as they found information and supports lacking and they felt alone and helpless upon arriving home.

The Seamless Transition project supports this recommendation. The project starts from hospital through to home, and was conducted in a community hospital in Mississauga, Ontario, to create a consistent, integrated, and patient-centred approach to hospital transitions (Mississauga Halton Community Care Access Centre [MH CCAC], 2016). The project was tested in the medicine program's two hospitals, one for nine months (Sept, 2014 to June, 2015) and the second for five months (Oct, 2015 to Feb,

2016) (MH CCAC, 2016). The key components of the Seamless Transition approach included an integrated care team, transition planning beginning at hospital admission, and enhanced care coordination with one person as a key contact between the patient and care team, and who is responsible for managing the transition plan (MH CCAC, 2016). The transition plan consists of the patient's written transition plan, using tools My Story, My Care Guide, and My Health Care Passport, and with the care team using the Plan of Care (MH CCAC, 2016). The transition team conducted daily discharge rounds, post-discharge phone calls, and/or home visits, as well as facilitated the accurate flow from community providers and hospital teams, and then back to the community providers. The results of the project were similar in both hospitals. Results from the first found a 52 percent reduction in readmission rates within 30 days with any diagnosis for patients in the Seamless Transition project's test group, compared to patients who did not receive the intervention. The second found a 57 percent reduction rate in emergency visits (MH CCAC, 2016). Patients discussed they felt better prepared to return home from the hospital, and that they did not have to repeat information to their various health care providers (MH CCAC, 2016). The project also improved the patient's experience, the hospital flow, and the relationship between the hospital and community providers (MH CCAC, 2016).

Recommendations for Future Research

Based on the key findings identified in the current study, future research should be conducted to explore the inconsistencies and difficulties during discharge planning, including communicating with different health care providers and what supports are required during discharge planning to eliminate ICs feeling unsupported and alone. As

well, further research should explore the burdens ICs face after discharge planning, such as patients' health issues, living arrangements, and safety concerns. IC burden is a major issue both before and after implementation of a hospital discharge planning process, and continual research is required to explore this lived experience. More research is also required to identify best practices for transitioning from a hospital setting to a safe community setting. For example, one may further explore the application of the TCM in providing discharge planning to patients with dementia and their informal caregivers. In using the TCM, further research can also assess the NP role in discharge planning, as well as effective communication between the key players of the interprofessional discharge team.

Conclusion

Discharge planning should begin immediately after hospital admission, with efforts to prepare the patient and their family for returning home. This gives discharge planners' ample amount of time to assess, plan, and prepare the patient and informal caregiver to return back to the home environment. Hospital discharge planners must effectively prepare elderly patients, as well as their informal caregivers, to transition from hospital to home. Providing necessary information, education, and community resources are important components of the discharge plan.

ICs want to be involved, and valued, in the hospital discharge plan. They want to receive information necessary to understand the health status and care needs of their loved ones, so they can continue to provide adequate care. Information sharing and communication practices between ICs and hospital staff, as well as between hospital staff and community agencies, must improve in order for discharge plans to be clearer and

better coordinated. In doing so, community services can be arranged in a timely manner. Improved communication should aim to better inform ICs about their role requirements during the hospital discharge plan, as this is a vital aspect of the planning process. This study illustrated ICs wanted to be informed about the patient's health status and available community resources. They were also seeking information and assistance for applying for retirement homes and long-term care homes. ICs also valued physical supports, including in-hospital transport and the pre-arrangement of transportation while leaving the hospital.

This study can help to improve discharge planning practices for dementia patients and their ICs by bringing to the foreground the impact ineffective discharge planning may have, as well as highlighting the importance of appropriate support. Hospitalization of a relative can be a stressful and traumatic event for the family, and working to alleviate this stress can occur by improving effective communication with ICs (Digby & Bloomer, 2014). ICs also appreciate regular information and updates about their relatives' condition and care priorities, as well as encouragement to be actively involved in decision-making with the health care team (Digby & Bloomer, 2014). Improving communication and supporting decision-making experiences of the IC will contribute to a successful discharge for the patients.

The APN-led TCM or NP model should be considered when conducting discharge planning. This model recommends a follow-up assessment and evaluation post-hospital discharge to reassess patient and IC needs, and to provide more information about resources (if required) in the community. A standardized model can prevent inconsistencies in discharge planning, including information sharing, system-navigating, and communication (Naylor et al., 2005). Moreover, having one key health professional

for ICs to go to during the discharge planning process could eliminate confusion and allow for better navigation. ICs should know to whom they could ask questions and obtain information from during the discharge plan. One such individual could be the NP. They may be involved in the discharge plan in collaboration with social workers, nurses, and other inter-disciplinary staff, as well as work to assess, diagnose, treat, educate, and prepare elderly patients including those with cognitive impairment for discharge home (Naylor et al, 2007). Bradway et al. (2012) acknowledged that APNs can overcome individual and system-related challenges by identifying both the patients' and ICs' educational (and other) needs, and then provide information and resources to prevent negative outcomes. Given the NP can assess, diagnose, and treat a patient with dementia, they can better assess their needs as required in the community. In addition, they can better educate ICs about dealing with BPSDs, and connect them with community resources and supports to reduce their burden. The NP can act as a key contact person to improve communication between patients and the health care team, as suggested by Digby and Bloomer (2014). Health care providers, including NPs, social workers, nurses, and other health care professionals, can all contribute to improving discharge practices. Discharge planning practices is just one aspect of improving care for persons with dementia and their ICs, however, ICs need better access to resources and community supports in order to take care of their loved ones in the community setting. Such issues must be addressed by provincial and federal policies.

The province of Ontario developed Ontario's Dementia Strategy to improve health care outcomes for those living with dementia, as well as that of their caregivers. There are six themes: supports for people living with dementia, accessing dementia

services, coordinated care, supports for care partners, well-trained dementia workforce, and awareness of stigmas related to dementia (MHLTC, 2016). The MHLTC has committed to increasing access to adult day programs by adding additional hours of care, as well as transportation to help people with dementia travel to the location of their local program. Also, the MHLTC (2017) is committed to enhancing caregiver respite services and enhancing behavioural supports, such as tools and techniques that address the behavioural symptoms of dementia. The Alzheimer's Society of Ontario developed a program called the First Link program, which connects individuals with available community supports (MHLTC, 2016). The federal government has also developed programs and strategies geared toward dementia patient.

Discharge planning is a tool used to safely transition patients from one place to the other, in this case from the hospital to the community setting. This study can add to research knowledge, as it has identified ICs lived experiences during hospital discharge planning. Current research findings suggest discharge planning practices should be improved for patients and their ICs by providing dementia caregivers with the tools, resources, and supports to aid them in their role.

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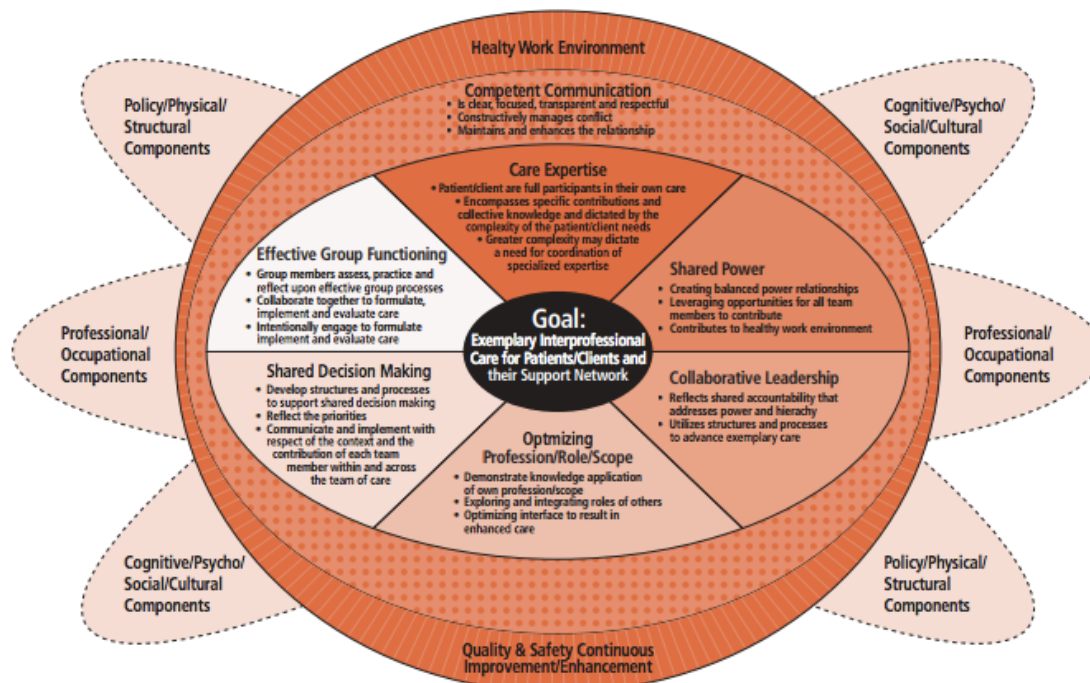
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Appendices

Appendix A: Conceptual Model for Developing and Sustaining Interprofessional Health Care



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Interprofessional Health Care: Optimizing patient, organizational and system outcomes. Retrieved from <http://rnao.ca/sites/rnao-ca/files/DevelopingAndSustainingBPG.pdf>.

Appendix B: Essential Elements of Transitional Care Model

1. Use of advanced knowledge and skills by a Transitional Care Nurse (TCN) who is an APN to deliver and coordinate care of high-risk older adults *within* and *across* all healthcare settings. The TCN is primary coordinator of care throughout potential or actual episodes of acute illness;
2. Comprehensive, holistic assessment of each older adult's priority needs, goals and preferences;
3. Collaboration with older adults, family caregivers and team members in implementation of a streamlined, evidenced-based plan of care designed to promote positive health and cost outcomes;
4. Regular home visits by the TCN with available, ongoing telephone support (seven days per week) through an average of two months;
5. Continuity of healthcare between hospital, post-acute and primary care clinicians facilitated by the TCN accompanying patients to visits to prevent or follow-up on an acute illness care management;
6. Active engagement of patients and family caregivers with a focus on meeting their goals;
7. Emphasis on patients' early identification and response to health care risks and symptoms to achieve positive outcomes and avoid adverse and untoward events that lead to acute care service use (e.g., emergency department visits, rehospitalizations);
8. Multidisciplinary approach that includes the patient, family caregivers and health care providers as members of a team;
9. Strong collaboration and communication between older adults, family caregivers and health care team members across episodes of acute care and in planning for future transitions (e.g., palliative care); and;
10. Ongoing investment in optimizing transitional care via performance monitoring and improvement.

Penn Nursing Science. (2014). Transitional Care Model. Retrieved from

<http://www.transitionalcare.info/essential-elements>.

Appendix C: Ethics approval from Laurentian University REB

This letter confirms that the research project identified below has successfully passed the ethics review by the Laurentian University Research Ethics Board (REB). Your ethics approval date, other milestone dates, and any special conditions for your project are indicated below.

TYPE OF APPROVAL / New X / Modifications to project / Time extension	
Name of Principal Investigator and school/department	Adwoa Owusua/Nursing
Title of Project	Alzheimer/Dementia Caregivers' Experience with Hospital Discharge Planning Post-Discharge
REB file number	2014-08-03
Date of original approval of project	Sept 10, 2014
Date of approval of project modifications or extension (if applicable)	
Final/Interim report due on: (You may request an extension)	Sept 10, 2015
Conditions placed on project	--

During the course of your research, no deviations from, or changes to, the protocol, recruitment or consent forms may be initiated without prior written approval from the REB. If you wish to modify your research project, please refer to the Research Ethics website to complete the appropriate REB form.

All projects must submit a report to REB at least once per year. If involvement with human participants continues for longer than one year (e.g. you have not completed the objectives of the study and have not yet terminated contact with the participants, except for feedback of final results to participants), you must request an extension using the appropriate LU REB form. In all cases, please ensure that your research complies with Tri-Council Policy Statement (TCPS). Also please quote your REB file number on all future correspondence with the REB office.

Congratulations and best wishes in conducting your research.



Rosanna Langer, PHD, Chair, *Laurentian University Research Ethics Board*

Appendix D: Ethical Approval from Trillium Health Partners REB

December 22, 2015
 Ms. Adwoa Owusua
 737 Savoline Blvd.
 Milton, Ontario
 L9T 0X6
 Dear Ms. Owusua,

RE: Alzheimer/Dementia Caregivers' Experience with Hospital Discharge Planning
 Post-Discharge (ID#658)
 Expedited Renewal Approval Expiry Date: December 11, 2016

This letter is to inform you that the renewal for the above-named research study has undergone expedited review, and has been granted approval effective December 11, 2015 by the Trillium Health Partners Research Ethics Board (REB) for a period of one year. The following documents submitted were included in this review, and have been approved until the expiry date noted above:

Research Protocol, version dated March 31, 2014 (date received April 27, 2015)

Appendix A: Research Semi-Structured Interview Questions, version date received April 27, 2015

Appendix B: Research Study Participation: Consent Form, date received February 25, 2015

Inclusion Criteria Checklist, date received November 9, 2014

Due to the lapse in continuing approval, the anniversary date for this study date has been reset from November 24, 2015 to December 11, 2015

During the course of the research, any significant deviations from the approved protocol (that is, any deviation which would lead to an increase in risk or a decrease in benefit to participants) and/or any unanticipated developments within the research should be brought to the attention of the Trillium Health Partners REB. In the event of a privacy breach, you are responsible for reporting the breach to the REB and the Trillium Health Partners Privacy Officer (in accordance with Ontario health privacy legislation – Personal Health Information Protection Act, 2004 (PHIPA)). Additionally, the REB requires reports of inappropriate/unauthorized use of information. As the Principal Investigator, you are responsible for the ethical conduct of this study.

Trillium Health Partners REB operates in compliance with the Tri-Council Policy Statement, ICH GCP Guidelines, PHIPA, and Part C, Division 5 of the Health Canada Food and Drug Regulations.

Appendix E: Inclusion Criteria

1. A primary informal dementia caregiver of a person diagnosed with Alzheimer's disease or dementia **admitted to hospital from home and discharged from hospital to home, including retirement home; excluding long term care.** **An informal caregiver is an individual who provides care and assistance, without pay, for family members and friends in need of support as a result of physical, cognitive, or mental condition (Canadian Institute for Health Information, 2010).*
2. A primary informal dementia caregiver of a person diagnosed with Alzheimer's disease or dementia that **received discharge planning by social worker** in emergency department or inpatient area.
3. Men or women caregivers over 18 years of age.
4. English speaking and able to provide consent.
5. Persons with Alzheimer's disease or dementia must be admitted with dementia related condition, for example, failure to cope, confusion, delirium, falls and related injuries as a result of cognitive impairment.
6. **Exclusion criteria:** Non-English speaking as well as caregivers' with a diagnosis of dementia or other health care conditions requiring home care. This eliminates issues of inability of providing consent due to cognitive impairment, along with the notion that the caregiver is not able to provide total care for a person with dementia (due to their own health care needs).

Appendix F: Consent Form



Laurentian University
Université Laurentienne

Background

This research will be conducted by Adwoa Owusua, RN, BScN and masters candidate with the knowledge and expertise of supervisor Dr. Sylvie Larocque with Laurentian University. The study will take place at Credit Valley Hospital with the aim of assessing caregivers of Alzheimer persons experience with hospital discharge plans. Exploring their experience with discharge planning and whether the hospital meets their in-hospital and post-hospital needs, can offer valuable knowledge about issues and matters related to service deliver with hopes of improving the health care system.

Purpose

- I understand the purpose of the study will be to better understand the experience of caregivers of Alzheimer/dementia persons post-discharge from the hospital.

Procedure

- I am aware that I will be getting a phone call from Adwoa Owusua in approximately two weeks to set up a telephone conversation at a time that is convenient for me.
- The telephone interview will require me to answer a few questions about my socio demographic characteristics such as gender, race and employment, relationship to patient, formal supports services pre or post hospital admission for the assistance of care giving, discharge plan received in hospital prior to discharge as well as my experience with discharge planning and being a caregiver of an Alzheimer person.

- The telephone interview will be for approximately 45-60 minutes.
- I am aware that the interviews taking place, as a part of this study will be tape-recorded to ensure all valuable information I share is captured accurately.

Risks and Benefits

- I understand I have agreed to participate in this study as someone who is caring for a person with dementia after receiving discharge planning.
- I am aware that as a caregiver of a dementia person, talking about my discharge experience may benefit myself and other Alzheimer caregivers as the information and suggestions I provide may be used to improve future discharge planning processes.
- However, if talking about my experiences as a caregiver of Alzheimer person makes me feel upset or if I feel that I need more community services, the researcher will encourage and assist me in accessing the following support to deal with these concerns. Information and contact number will be provided to me for Alzheimer's Society- Peel (60 Briarwood Avenue Mississauga, ON L5G, telephone: 905-278-3667, email: n.bhamra@alzheimerpeel.com).

Confidentially

- I am aware that at no time will my name be identified in the recording or reporting of the information shared and that any parts of the interview that are included in written public articles, presentations, and/or reports that come from the research will be anonymous.
- I am aware that all data collected (socio-demographic, relationship to patient, information about formal supports, hospital discharge plan received prior to discharge as well as my experience with discharge planning) will be securely retained by the

researcher, stored on to a USB key with password entrusted only to researcher and supervisor for 5 years, after which the USB will be physically destroyed along with paper documents cross-shredded.

- I am aware the digital audiotapes will be erased and audio recordings recorded over once transcribed. The audio-recorder will be stored in a locked cabinet in a locked room in the researcher's home.

Voluntary Participation

- I am aware that my participation in this study is voluntary and I may withdraw my participation prior to the interview.
- If there are any questions I do not feel comfortable answering, I do not have to do so.
- I am aware that withdrawing from the study will have no impact on any of the services I am, or the person I am caring for, are presently receiving.
- I am aware that once I withdraw my participation from the study post-interview the information collected from me will be included in the study's results.

Questions About the Study

- I have read the consent form and had the content explained to me by Adwoa Owusua a Laurentian University Masters of Nursing Student.
- I have had the opportunity to ask questions related to this study as well have received satisfactory answers to my questions.
- I was informed that I may contact the Research Ethics Office at the Laurentian University Research Office toll free at 1-800-461-4030 ext.3213 or email ethics@laurentian.ca regarding any ethical issues or concerns I may have about the research itself.

- This study has been approved by the Trillium Health Partners Research Ethics board.

If you have any concerns about your rights as a participant in this project, you can call the Trillium Health Partners Research Ethics Board, [905-848-7580](tel:905-848-7580), x1682.

I, _____ agree to participate in the following study.

NAME: _____ (please print)

SIGNATURE: _____

DATE: _____

Contact Information of Researcher:

Student investigator: Adwoa Owusua (RN, BScN, MScN candidate) Trillium Health Partners and Laurentian University, 1-800-461-4030 ext. 3804

Email: aowusua@laurentian.ca; aowusua@trilliumhealthpartners.ca

Thesis Supervisor: Sylvie Larocque (RN, PhD, Associate Professor, Laurentian University), 1-800-461-4030 ext. 3804

I am interested in receiving a copy of the research findings via (choose one)

_____ a) email

_____ b) hard copy

Appendix G: Semi-Structured Interview Questions.

1. What is your relationship with the patient?
2. What is your gender, race and employment status?
3. Did you receive formal supports services pre or post admission for the assistance of care giving? If yes what are these supports?
4. What is your experience of being a caregiver?
5. Can you talk to me about your discharge experience?
6. What information and resources was provided to you during your in-hospital discharge plan?
7. Did you receive any resources related to caring for a patient with dementia?
8. What was the most helpful aspect of the discharge plan? What was the most difficult?
9. Anything that you could benefit from that you did not receive?
10. Any suggestions for discharge planning? Any improvements?